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HOW DO ADOLESCENTS WITH SICKLE CELL DISEASE
PERCEIVE THEIR DISEASE?

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To my mother for her love, faith, confidence,
patience, support, understanding and encouragement
throughout my life.

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ABSTRACT

The purpose of this study was to find out how do adolescents with sickle cell disease perceive their disease. The study was conducted in Bahrain. The convenience sample (n=10) consisted of adolescents age 13-15 years who have sickle cell disease. The sample consisted of equal distributions of males and females. Utilizing qualitative methodology, the data was collected through face to face interviews using an interview guide and was tape recorded and was conducted by the investigator. The data was analyzed using content analysis. The data was categorized into three major categories, general information about sickle cell disease, effect of sickle cell disease on daily living and effect of sickle

cell disease on future plans and decisions. The subcategories were analyzed within each major category. The results showed that all the participants did not know the necessary information about sickle cell disease. The results also indicated that the health care provider did not provide the adolescents with sufficient information on sickle cell disease. All the adolescents in the study had a misperception about sickle cell disease and its effects on them now and in the future. Recommendations included the necessity of providing the adolescents with sickle cell disease with adequate information regarding their disease, developing and implementing a special health education program for children with sickle cell disease, and planning and implementing inservice education sessions for nurses who take care of patients with sickle cell disease.

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CHAPTER I

STATEMENT OF THE PROBLEM

A. Introduction:

The State of Bahrain is composed of six major islands situated off the coast of the Arabian Gulf. The total area of the state is 669.26 sq. km. The main island (about 50 km long and 13-35 km wide) contains Manama, the capital of Bahrain. The climate of Bahrain is characterized by high summer temperatures, scanty and irregular fall rainfall, high relative humidity and persistent prevailing winds from the northwest. For the year 1982, a maximum temperature of 44.5C degrees was recorded in the month of July. Relative humidity varies between a minimum of 40% and a maximum of 89%.

The state has a population of 417,210. Thirty two percent of the population consists of expatriots hired for the national building programs because of the critical shortage of manpower. The population is expected to double by the year 2000. The crude birth rate is 29.4/1000 pop. The majority of the inhabitants live in the rural area and 7.8% live in urban areas. The population under the age of 15 years is 41.2%, which indicates a young population. The literacy rate is 73% (State of Bahrain-Ministry of Health Annual Report 1985).

The national economy is centered around oil production and related industrialization such as petroleum refining, petrochemical industry development, aluminum smelting, agriculture and banking.

By government law, all residents, citizens and non citizens in the country have the right to comprehensive health care. The government provides free primary, secondary and tertiary health care to all residents of Bahrain. The technical and financial responsibility for providing such care rests mainly with the state, with the participation of the private sector.

The health problems and disease patterns in Bahrain reflect a combination of the ones found in both developing and developed countries. Based on the inpatient hospital records, the major categories of morbidity are complications of pregnancy, child birth and the purperium, respiratory (eg. asthma), circulatory (eg. sickle cell anemia, glucose-6-phosphate dehydrogenase (G6PD), thalassemia), digestive and genitourinary disease. The major causes of mortality, based on registered deaths, are the circulatory diseases, neoplasms, respiratory and infectious disease.

In Bahrain the religion of the country is Islam. There are many customs which are still being practiced and used by the Bahrainies. One of these customs is endogamy. Endogamy is marriage within the same family;

that is, marrying one's father's brother's daughter or son. This type of marriage is the one traditionally performed mostly in villages and among closely knit communities. The percentage of this kind of marriage usually ranges between 3% and 8%. Because of inter-family marriage, there is a high percentage of inherited disease, such as hypertension, diabetes and circulatory disease.

One of the most common anemias in Bahrain, sickle cell anemia in neonates born to Bahraini mothers, was found to be 2.1% and sickle cell trait was 11.2% (Mohammed et al. 1986) compared to the United States where the incidences of sickle cell trait and sickle cell disease in the black population is 1:10 and 1:400 respectively (Scipien 1986). Both sexes, male and female, are affected in Bahrain. Every newborn is screened for sickle cell anemia and G6PD whether there is a history of disease in the family or not.

In Bahrain, much effort by the government and the Ministry of Health is being directed toward educating the population about sickle cell anemia. This is done through genetic counseling in hospitals, conducting seminars, and conducting panel discussions, which usually include pediatricians, hematologists, nutritionalists, genetic counselors and social workers. Education is also through television, the radio, and

presentations at clubs and associations all over the country, and specifically in villages where the incidence of sickle cell disease is higher. Education is done also through newspapers, pamphlets and posters. This education is mainly focused towards the parents and relatives, and very little attention is given to the children who suffer from sickle cell disease regarding the disease, treatment and prognosis. Therefore it is important to know what adolescents with sickle cell disease know about their disease.

B. Statement of the Problem:

The question to be explored in this study is, how do adolescents with sickle cell disease perceive their disease?

C. Research Questions:

1. What do the Bahraini adolescents know about sickle cell disease?
2. What do they do to keep themselves healthy?
3. Who explains sickle cell disease to them?
4. To whom do they talk about their disease?
5. How are they being treated at home and school?
6. How do they feel about the way they are treated?
7. How does the disease effect their future plans and decisions concerning:

- a. education
- b. work
- c. personal life

D. Definition of Terms:

For the purpose of this study:

1. Adolescent: Male or female, 13-15 years of age, with sickle cell disease.

2. Sickle cell disease: A severe hereditary anemia occurring among the offspring of parents who both have sickle cell anemia. It is a chronic, incurable disease including several hemoglobinopathies.

Hemoglobin (Hb)SS, HbSC and Hb Sickle-beta-thalassemia (vichinsky 1980).

3. Perception: Awareness or understanding, based on knowledge gained through the senses.

E. Rationale:

The high incidence of hereditary anemias in developing countries creates a demand on the health resources. In Bahrain, the hereditary anemias are becoming a major public health problem.

Mohammed et. al. (1987) conducted a project which began in October 1984 and ended in December 1985. During this period of time, cord blood samples were collected and analyzed daily. A total of 10,327 or 80% of all neonates born to Bahraini mothers in Ministry of

Health Maternity Hospitals were screened. The figures consisted of 80% of all neonates born in that time span. Blood samples were analyzed for glucose 6 phosphate dehydrogenase deficiency (G6PD) enzyme, hemoglobinopathies which include sickle cell anemia, and minor thalassemia. The incidence of sickle cell anemia in these neonates was found to be 2.1% while that of sickle cell trait was found to be 11.2%. The annual live births in Bahrain about 12,000 and the figure used for the project were 10,327 which mean that 240 neonates will be born annually with sickle cell anemia and 1,300 neonates will be individuals with sickle cell trait.

Musaiger, et. al. (1986) conducted a study whereby all records of patients with hereditary anemia who were admitted to the Salmaniya Medical Center in Bahrain for the period 1980-1982 were reviewed and analyzed. The data for the study was obtained from the Salmaniya Medical Information System. The data related to hereditary anemias was correlated with age, sex, nationality and place of residence of hospitalized patients with such disease. The hereditary anemia which included spherocytosis glucose 6 phosphate dehydrogenase deficiency, thalassemies and sickle cell anemia were grouped under the heading hereditary anemia in the Salmaniya Medical Information System.

Musaiger et. al. (1986) reported that in the year

1982, 25.7% of the hospitalized anemias were in the age group 1-4 years, compared to 28.5% for the age group 5-9 years and 10-19 years respectively. Whereas only 18.8% of the hospitalized anemias were older than 19 years. In 1980, 64.9% of the hospitalized anaemias were males compared to 35.1% females. However, the proportion of males decreased to 59.5% in 1981 compared to 40.5% females and 56.1% in 1982 compared to 43.9% females. The nationality distribution of hospitalized patients with hereditary anemias showed that almost all the anemias were Bahrainis (98.1%, 97.9% and 99%) for the year 1980, 1981 and 1982 respectively. It was also found that the prevalence of hereditary anemias was higher in rural areas than urban ones.

Hereditary anemias are a problem of concern in Bahrain since these diseases are both common and chronic. The hereditary disease like sickle cell disease is possible to be controlled through suitable measures like proper health education, genetic counseling and antenatal diagnosis. The health education should be aimed toward educating the whole population and special programs should be organized for children with sickle cell disease.

Although no study has focused specifically on the children or adolescents with sickle cell disease and how they understand and perceive their disease, some studies

have been done on children's perceptions of illness and hospitalization. For example, Perrin (1981, p. 841) in the study on children's understanding of illness, states that children's ideas regarding illness frequently involve punishment, guilt and self blame. Hospitalized children often ascribe the cause of their illness to disobedience of parental commands and interpret this hospitalization as rejection or punishment. Another study conducted by Brewster (1942) concluded that in order to design an effective program for chronically ill pediatric patients, hospital personnel must put information gathering before information giving. They must find out how each child views the cause of his illness, treatment, prognosis and how the child feels about the disease.

We can conclude from the literature on children's understanding of illness that children or adolescents are very likely to have misperceptions or misconceptions about their disease and how it affects their lives. So, it is important to find out how these adolescents who have sickle cell disease feel, know and understand their disease, especially at this age (13-15 years), when they have to choose their future education by selecting which field of education they would like to study (science, literature or other) in high school.

F. Scope and Limitations:

This study is a descriptive study of adolescent subjects with sickle cell disease. Subjects included are those diagnosed with and treated for a chronic disease, specifically sickle cell disease during the developmental stages of adolescence. The sample is a convenience sample of adolescents with sickle cell disease and did not include any other chronic illness.

The sample was limited to ten subjects. Therefore, the findings of this limited sample will be too narrow in scope to be applicable for the general population of chronically ill adolescents. The study was geographically limited to the State of Bahrain, and was further limited to include only subjects whose native language is Arabic.

Lastly, for this study there was no specific article or study in the literature that dealt with adolescent perception of sickle cell anemia; therefore, a qualitative study has been done which has its own limitation such as a small, convenient sample. The data are not appropriate for establishing vigorous testing hypotheses.

CHAPTER II

REVIEW OF LITERATURE

A. Introduction:

The literature review will be divided into three major sections. The first section will discuss sickle cell disease, biochemical origins, inheritance pattern, diagnosis, treatment and prognosis. This will be followed by the developmental tasks of adolescents, which will be followed by a review of the literature concerning children's and adolescent's perceptions of chronic disease.

B. Sickle Cell Disease:

Sickle cell disease is a generic term applied to any disorder characterized by red blood cells containing sickle hemoglobin (HbS), an abnormal hemoglobin. Hemoglobin is a complex protein responsible for oxygen transport. Human red blood cells normally contain at least three types of hemoglobin (Hb), namely adult hemoglobin (HbA and HbA2) and fetal hemoglobin (HbF). Fetal hemoglobin is gradually replaced by HbA during the last 2 months of fetal life and first 6 months after birth. The major adult hemoglobin, HbA, normally comprises about 95 percent of the total hemoglobin in the red blood cell while HbA2 represents 3 to 5 percent

of the hemoglobin.

Sickle cell disease occurs in the person who has inherited two abnormal genes, referred to as the homozygous state. Persons with sickle cell disease have red blood cells that contain 80 to 100 percent HbS, a condition that is associated with high morbidity. The presence of significant amounts of HbS within the hemoglobin molecule of the red blood cell deforms the round shape of the cell into a sickle or crescent when the supply of oxygen is decreased. As the red cell sickles, it becomes rigid, obstructing blood flow in the microcirculation. The deoxygenation of blood that ensues is associated with an increase in blood viscosity, producing stasis and tissue hypoxia. This "vascular occlusion" initiates destruction that affects vascular, intravascular and perivascular compartments (Gradolf 1983). The intravascular sickling can occur anywhere in the body, but marked stasis is most likely to occur in organs in which the blood flow is slow, such as the spleen, bone marrow, liver and penis. Organs in which the oxygen uptake is high, such as the brain and kidneys, are also at risk for intravascular sickling (Gradolf 1983).

Sickle cell disease is an hereditary disease that is transmitted genetically in an autosomal recessive manner. The abnormal gene comes either from the mother

or father, or both. If only one parent has sickle cell trait, for each pregnancy there is a 50 percent chance each child will have normal hemoglobin, 50 percent chance each child will have sickle cell trait, and no chance any child will have sickle cell disease. On the other hand, if both parents have sickle cell trait, for each pregnancy there is a 25 percent chance each child will have normal hemoglobin, 50 percent chance each child will have sickle cell trait, and 25 percent chance each child will have sickle cell disease.

If one parent has sickle cell trait and the other has sickle cell anemia, for each pregnancy there is no chance any child will have normal hemoglobin, 50 percent chance each child will have sickle cell trait, and 50 percent chance each child will have sickle cell anemia. If both parents have sickle cell disease, all their children will have sickle cell disease (Myrie 1983).

The most common symptoms of sickle cell disease are the painful crises affecting the extremities, back, chest or abdomen. Typically these crises (with the exception of the hand-foot syndrome) begin at age 4 or 5 and occur frequently during adulthood. There is a wide spectrum in frequency and severity. In infants the hand-foot syndrome (dactylitis) is a result of ischemia of the marrow of the fingers and toes. These episodes are characterized by painful swelling and erythema of

the hands and feet. This is often the initial manifestation of the disease (Rooks 1983). Pain in the extremities, chest and back results from small areas of infarction in the bone. The pain is usually severe and continuous; it usually lasts three to four days. There is usually tenderness and mild edema at the site. A low grade fever may accompany the crisis (Walters 1983).

Infarctions of the lung seemingly are associated with ensuing pulmonary infection. The incidence of pneumonia in patients with sickle cell disease is about 100 times greater than in the general population. The most common event seen in 38 percent to 45 percent of patients with sickle cell disease is an acute abacteremic, febrile episode with a pulmonary infiltrate. Vasoocclusion of the central nervous system manifests as cerebrovascular accidents, seizures and visual disturbances. These occur in 13 to 26 percent of sickle cell patients. Eighty percent of these occur in patients less than 15 years old (Jackson 1972).

There is no cure for sickle cell disease. Treatment is supportive and symptomatic. The painful or thrombotic crisis is generally treated with bed rest, analgesics and hydration to increase blood volume and encourage the mobilization of stagnant sickle cell. Antibiotics are used when infection is present. Transfusion therapy is generally employed in cases of

severe anemia, such as that accompanying an infection, in sequestration and aplastic crises or prior to surgery.

Patients who have very large spleens and who require excessive transfusions, may have a splenectomy performed. These children are then placed on prophylactic antibiotics for an extended period. The pH is also carefully monitored, as acidity promotes sickling. Alkaline fluids are given at times, especially in priapism. Children are encouraged to force fluids, particularly orange juice, which is alkaline in the body, and avoid substances like aspirin.

C. Developmental Tasks of Adolescents:

The period of adolescence is characterized by developmental changes and issues in three major areas: physical and sexual maturation, changing societal expectations and psychological adjustment (Sugar 1979). Achieving physical and sexual maturity is believed to be the most important developmental task of adolescents. Some theorists of the the adolescent period believe pubertal changes are responsible for stimulating the turmoil characteristic of adolescents (Blos 1962). Physical and sexual development, physical maturity, health and personal appearance all contribute to the adolescent's perception of himself during puberty (Rosenberg 1965).

A recent study by Museiger et. al. (1987) showed that Bahraini children are shorter in stature and lighter in weight than the North American children for all age groups (6 to 18 years). The mean height of Bahrain is at or below the 25th percentiles of the American Standard (NCHS) while that of weight ranged between 10th and 25th percentiles for boys, and 25th and 50th percentiles for girls.

Societal influences greatly effect the developing adolescent. The adolescent must achieve numerous other developmental tasks. These include scholastic success, educational/vocational goal setting, successful social relationships, independence from family without antagonism and achievement of socially responsible behavior (Rosenberg 1965). Society urges its adolescents to achieve these developmental tasks and to become adults. But society does not have clear expectations for the adolescents. Sometimes he is treated like an adult; at other times, he is treated like a child.

This role ambiguity and confusion leads the adolescent to search for his own identity. Erikson (1964) views the period of adolescence as a search for identity. The peer group has a positive adaptive function for the confused adolescent. Ausubel (1955, p. 34) stated that:

Besides providing compensatory status, it plays a major role in facilitating emancipation from the home, transmitting social class values and focalizing resistance against adult standards and authority and serves as the principal institution of the adolescent period.

The adolescent identifies himself with a group that has its own selective member who shares commonalities. Belonging to a group, having stable friends, being socially acceptable, and having successful social relationships are extremely important to his psychological adjustment (Ausubel 1954; Blos 1962).

There are differences between developmental task achievement in early and late adolescents. Early adolescence is characterized by a heightened concern with bodily changes and identification with a large peer group of adolescents of the same sex. As adolescent development progresses, educational/vocational goals are developing, heterosexual relationships are evolving, individual sexuality is addressed, and marriage and family life are contemplated (Ausubel 1954; Offer 1969). Thus, adolescence is a period of rapid physical and psychosocial growth and development.

According to Piaget (1973), the stage of formal operations starts at 11 or 12 years of age and continues through adulthood. The adolescent has the ability to consider possibilities even if they have not experienced them in a real situation. The adolescent can solve

hypothetical, mental and verbal problems using logical thinking. He can deal with the past, present and future and understand causality.

D. Perception of Chronic Illness:

There has not been much written regarding childrens' perceptions of health. Using Piaget's theoretical framework of cognitive development, Perrin (1981) demonstrated that conceptions of illness undergo considerable development during childhood. In this study, 128 healthy children attending kindergarten through eighth grade were asked a series of standardized questions about illness. Children's response varied widely at all ages, but there was a systematic progression with age in their understanding of illness-related concepts.

Kindergarten children typically understand illness causation as magical or as the consequence of their transgression of rules. In the fourth grade, children believed all illness to be caused by germs, whose mere presence is sufficient to make a child sick. The complexity of the mechanisms that must interrelate to cause illness is not understood until the eighth grade. At approximately 12 or 13 years of age, children begin to understand that there are multiple causes of illness, that the body may respond variably to any combination of agents, and that host factors interact with the agent to

cause and cure illness.

Perrin concluded that in the development of understanding about illness, childrens' ideas regarding illness frequently involve punishment, guilt and self blame about disobedience of parental commands. Perrin's results may have suffered from the sample he selected. It was a suburban public school system in upstate New York in an isolated area. In addition, his study was conducted during an individual one-time interview, lasting from 30 to 60 minutes, which may have limited the validity of using kindergarten students with their short attention spans.

The first study of children's health attitudes and behaviors was done by Mechanic in 1964. The study involved 350 children and their mothers living in Madison, Wisconsin. The sample included 175 fourth grade children (9-10 years of age) in five schools and 175 eighth grade students (13-14 years of age) chosen randomly from three schools. Data was collected on several family-social characteristics: mother's attitudes towards the children's health, their generalized values about health, attitudes toward doctors, use of medical care and family illness. Data obtained from children included their willingness to report symptoms, and their attitudes toward health and medical facilities. The major part of the study aimed

at investigating how health related behavior patterns developed. It was hypothesized by Mechanic that children's patterns of illness behavior were influenced by child rearing practices, family stress and family definition of health resources.

Mechanic's data provided some interesting information even though he was unable to show any statistical significance for his hypothesis. The data showed that age and sex were significant determinants of children's responses. Males at both age levels were less afraid of getting hurt and reported less attention to pain than females, and these trends continued with age. The mother's educational achievement was the best predictor of social status and her attitudes towards health and illness depended upon her educational status. There were striking associations between mother and child's illness behaviors. Mothers with a high inclination to use medical care, when compared to mothers with lower inclinations to do so, were much more likely to take their children to the doctor frequently and to allow their children to assume a "sick role." (Mechanic 1964). No cultural influences were examined.

The next study found in the literature was conducted in 1962 by Gellert. Here, 96 children from 4 to 16 years of age were tested on their concept of the function of the human body. In most cases, the age for

giving correct answers to questions about the anatomy and physiology of the body increased sharply around the age of 9 when children seemed to perform at levels of cognitive development higher than predicted (Gellert 1962).

Gochman's (1970) studies on "children's perceptions of vulnerability to illness and accidents" describes perceived vulnerability to accidents and sickness. A sample of 134 children from 7 to 17 years of age were asked about the likelihood of having certain things happen to them, such as accidents, influenza, toothaches and colds. A child's perceived vulnerability was found to be consistent across several types of health problems. Gochman believed this might constitute evidence of some personality characteristic and if longitudinal research confirmed the stability of these expectancies, then attempts to change levels of perceived vulnerability in children might have to begin far earlier than they do. He suggested that children in primary grades might need to be approached with some type of intervention.

The results also indicated the apparent instability of younger children to deal with health as a concept. Some differences in responses were found between the sexes; boys showed significantly lower expectancies of remaining healthy and perceived themselves less

vulnerable than females (Gochman 1970).

Kellerman, Zultzer, Ellenberg, Dash and Rigler (1980) compared 349 physically healthy adolescents with 168 chronically ill (oncology, cardiac, diabetic, cystic fibrosis nephrology and rheumatology diseases) adolescent in terms of anxiety, self esteem and perception of control. The results of this research suggest no significant difference between healthy and chronically ill adolescents on the state-trait anxiety inventory or the Rosenberg scale of self-esteem. However, a significant difference was found between ill and healthy groups in terms of locus of control. Ill adolescents were more external (the oncology group being the most external) in their perceptions of health locus of control (Kellerman, et al, 1980, p. 129).

Results of the large and varied sample of (this) present study lend further confirmation of the essential psychologic normalcy of most youngsters with chronic and serious disease... The lack of responses indicating psychologic decrement may be due, partially, to high levels of adolescent denial. Such denial need not be looked upon as inappropriate, adaptive process" (Kellerman, et al, 1980, p. 130).

Another study, done by Bibace in 1980, was able to delineate six categories of illness based on the explanations of groups of four year olds, seven year olds and eleven year olds. These six categories were consistent with Piaget's three major stages (pre-logical

stage, concrete operational stage and formal operational stage) of cognitive development past infancy and followed the developmental of causal reasoning. Using 24 children in each of the three groups, an interview protocol with 12 questions was set up. The child's notions about several common illnesses, such as a cold, heart attack, measles, headache and pain, as well as the child's explanation of personal illnesses, or illnesses of relatives or friends, were investigated. The data indicated that the degree of personal control a person perceives is directly related to his, or her, cognitive developmental status. Hence, children's sense of personal control increases with development.

Children in the pre-logical stage gave illness explanations based on phenominism (external concrete phenomena which may co-exist, but not affect, i.e., "get colds from the sun") and contagion (illness comes from objects or people close to the child). In the concrete operational stage, illness explanations focused on contamination (cause is viewed as a person, object, or action external to the child, which has an aspect or quality that is "bad" or "harmful" for the body), and internalization (illness is located within the body, but described in vague and nonspecific terms, indicating confusion about internal organs and functions). At the formal operational level, the child gave physiologic and

psychophysiologic explanations (the child is aware not only of internal functioning, but also that a person's thoughts or feelings can affect the way the body functions).

Bibace concluded that this information has many implications for health teaching and utilization that of such information about the development of concepts of health and illness is needed to design meaningful educational strategies and material consistent with the child's developmental status (Bibace 1980). Again, this study was based on a small, sample size, utilizing only seven students in each of the three groups. In addition, bias may have been introduced by utilizing participants from outpatient clinic.

In yet another study, Brewster (1982) investigated the relationship between cognitive development and children's understanding of the cause of illness, intent of medical procedures and the role of the medical staff in order to provide a more adequate foundation for patient education. The cognitive developmental theory of Piaget was used to explain and predict the child's understanding in these areas. The four stages according to Piaget's theory are: sensory motor (infancy), pre-operational (early childhood), concrete operational (middle and late childhood), and formal operational (adolescent and adulthood).

In this study, three hypotheses were investigated. The first predicted that the child's understanding of the cause of his illness would be related to his understanding of the physical cause and affect and that his understanding of the intent of medical procedures and the role of medical personnel would be related to his general understanding of intentionality and social roles. The second hypothesis predicted that there would be increasing cognitive maturation as a function of age. The third predicted that the child's understanding of matters in high affect areas, (eg. concerning his disease), would lag behind his comprehension in low affect even though these involve similar cognitive skills.

A group of 50 chronically ill children between the ages of 5 years and 13 years, 11 months served as subjects. The 50 subjects included 26 white children, 22 black children, one Arabic child and one Mexican child. Each child had been hospitalized at least once. There were 26 girls and 24 boys in the study. All children had normal IQ's and were in regular classes in school. The children had a variety of chronic diseases. The sample included children with juvenile diabetes, asthma, leukemia, osteosarcoma, cystic fibrosis, systemic lupus erythematosus, congenital heart disease, congenital kidney disease, juvenile rheumatoid

arthritis, congenital bilateral dislocated hips and sickle cell disease.

Children were interviewed near the end of hospitalization when their conditions were stable. Five cognitive tasks were administered to each child. Task 1 explored the child's level of logical thinking; Task 2 determined the child's grasp of physical cause and effect; Task 3 probed the child's ideas about cause of illness; Task 4 concerned the child's grasp of social role perspectives; and Task 5 investigated the way that the child might view the role of medical personnel and the intent of medical procedures.

The interviews averaged 45 minutes. Results indicated a correlation coefficient of responses among tasks. Analysis of variance yielded an age related maturation of responses. No significant difference in level of responses between high and low effect cognitive task was found. There was a three stage sequence of conceptual development in understanding cause of illness: (1) illness is caused by human action, (2) illness is caused by germs, (3) illness is caused by physical weakness or susceptibility. A parallel three stage sequence of understanding of the intent of medical procedures was discerned: (1) the child views procedures as punishment, (2) he/she correctly perceives the procedures, but believes that the staff's empathy

depends on the patient expressing pain, (3) the child can infer both intention and empathy from the medical staff. Specific illness, sex of the child, and length of hospitalization did not affect the child's level of response.

Brewster (1982) concluded that in order to design an effective program for chronically ill pediatric patients, hospital personnel must put information gathering before information giving, and staff members must find out precisely how each child views the cause of his illness and the reasons for treatment. Good patient education progress tailors information to fit each child's cognitive and emotional needs; also, it is more important for the medical staff members to hear and comprehend what the patient is saying than for the patient to hear and comprehend what the medical staff members are saying (Brewster 1982).

Huntley (1983) studied a group of sickle cell diseased young adults. The primary focus of the study was counseling and its effect on self esteem and feelings about the future for this sickle cell diseased population. Thirty young adults with diagnosed sickle cell disease volunteered to participate in this study. All subjects, both males and females, were between the ages of 18 and 25 years. The young adults who participated in the study were those who had received no

counseling or who had counseling directed toward coping with the effects of sickle cell disease between the ages of 13 and 19. Young adults were used in the study in order to obtain their perspective over time of the effectiveness of adolescent counseling, if received, on their present life and future outlook.

For the purpose of collecting data, a questionnaire developed by the researcher, and a standardized self-concept scale (TSCS) were administered to all young adult subjects. In order to answer all items on the questionnaire, the subjects were asked to recall some of their sickle cell disease adolescent experiences and the effects these experiences had on their present life and perceptions, as well as their feelings about the future.

The primary results of this study showed a positive relationship between high self esteem scores of young adult subjects and their counseling experiences. Counseled subjects more frequently indicated greater hope for their future than did non-counseled subjects. All subjects indicated that there was a need for counseling, and of all support systems, family support was the strongest for sickle cell disease subjects, regardless of the family constellation or family definition. Conclusions based on the findings indicated that counseling appears to have been a contributing factor in raising the level of subject's self esteem and

confidence in the future.

As with many chronic illnesses the persons affected with sickle cell disease are also at risk of developing adverse psychological consequences as a result of their own and others interpretations of the disease. Not all people with sickle cell disease are alike physically or psychologically, but just as there are some commonalities in physical characteristics, the same is true with psychological profiles.

Williams, Earles and Pack (1983) stated that adolescents need love and support to prepare themselves for adult relationships and responsibilities. Many sickle cell patients, like many chronically ill persons, do not have these needs met and experience an adolescence of unhappiness, rejection, failure and loss of self esteem. Some of the contradictions inherent in adolescents are exacerbated by chronic illness such as sickle cell disease. For example, despite social and physical maturity, young people are encouraged to remain dependent in order to complete formal education. It is possible that absences from school have held a young person with sickle cell disease back from normal grade advancement. This obviously creates a longer period of dependency. Also, during acute forms of the illness, regression to infantile behavior encourages those around him to treat the person like a child. This interaction

heightens the child-adult contradiction, the conflict between dependency and independency (Williams, et. al., 1983).

Leavell and Ford (1983) noted that during adolescence the peer group is most influential. Adolescents are more concerned about their physical appearance than other aspects of themselves and self consciously compare their bodies to those of their peers. For the adolescent with sickle cell disease, this peer pressure can be painful. Frequently, adolescents with sickle cell disease mature later than their contemporaries. Although both sexes are affected, boys seem to suffer more than girls. Small size and immaturity are not the only physical concerns of the adolescent with sickle cell disease. Many suffer other disfigurements secondary to the disease. Jaundice, dental deformities and surgical scars are often sources of embarrassment (Leavell & Ford, 1983).

Jelneck (1977) stated that depression is a common and serious complication of sickle cell disease. The adolescent with sickle cell disease may experience particular feelings of fear and anxiety, depressed by the prospect of being ill for the rest of his life or having a potentially fatal disease. Depression may affect an individual's ability to manage his disease and personal life. He may become dependent on drugs,

CHAPTER III

METHODOLOGY

A. Research Approach and Design:

Qualitative research methodology was used in this study. The design of the study was descriptive and was conducted to explore adolescents' perception of their sickle cell disease. Due to lack of information and literature on this subject, this study was designed to gather information from adolescents and to understand how they perceive sickle cell disease. The population was comprised of Bahraini adolescents with sickle cell disease.

B. Sample:

A convenience sample was selected from adolescents with sickle cell disease in Salmanya Medical Center in Bahrain. The sample consisted of participants who had been admitted previously and at least once to the hospital and who did not have any other chronic illness other than sickle cell disease. There was an equal distribution of males and females, all Arabic speakers.

The age of the participants ranged from 13 years to 15 years. This age range was considerably narrow. However, after finishing intermediate school, which is usually in that age range, and before entering high school, Bahraini students are allowed to choose what

they wish to study as their specialty leading to professionalism (e.g. if they would like to be physicians or engineers, they should choose a specific field. For other professions, students might choose literature, the arts or computer sciences.) By the age of 13 to 15 years, the adolescent has chosen his future education. For a student in that category, having a chronic disease like sickle cell disease might have an effect on such a decision.

C. Gaining Access to the Participants:

Official permission of the Medical Record officer in Salmany Medical Center was sought to use medical records to get the names and addresses of potential participants. In the Medical Record Center, records of patients with sickle cell disease were pulled out and prepared by the Medical Record staff. The investigator went through all the records that were pulled out and excluded records that did not meet the study criteria.

Eighteen subjects who met the criteria of the study were selected. The investigator reviewed each of the 18 records and read briefly about each participant's condition and wrote down the participant's names, ages, sex, addresses, telephone numbers and the last time they had been admitted to the hospital. The investigator then contacted each participant either by phone or by

going to their home. After explaining the study to the parents and participants, the investigator obtained their permission to participate in the study.

D. Data Collection:

Face to face interviewing with an interview guide was used to answer the research question: How do adolescents with sickle cell disease perceive their disease? The interview guide which probed for the participants' perceptions about sickle cell disease (see Appendix B), was developed by the investigator. Under the advisor's instruction, the interview guide was clarified several times before conducting the interview process. It was tested in a pilot interview with two Bahraini adolescents with sickle cell disease and these two were not included in the present study. The two adolescents met the study criteria. Some revisions were made in the interview guide. The interview guide was then translated into Arabic by the investigator and another individual separately and both translations were similar.

All the interviews were conducted by the investigator and in the participant's homes. In order to get the participants answers to the interview questions without being influenced by any external effect, the investigator did not introduce herself as a nurse but rather as someone who was studying in the

United States and conducting a research study in the field of sickle cell disease. When the interview was over, the investigator did tell them that she is a nurse.

All the interviews were conducted in Arabic and were tape recorded. The interviews were conducted over a period of six weeks during the summer of 1987 and they ranged in length from 35 to 45 minutes.

The investigator spent time at the beginning of the interview explaining to the participants that she was interested in their ideas, knowledge and opinions about sickle cell disease and that there was no right or wrong answer.

In all the interviews the mother or the mother and a sibling (a third party) were present at the beginning. The investigator explained the study to them as well as the importance of interviewing the participant alone. When the interview was over, the mother was called back and at that time, the demographical data was obtained. At the end of the interview, all the participants and their mothers had different questions about sickle cell disease. The investigator spent time explaining to them about the disease.

E. Data Analysis:

Content analysis was performed based on taped

interview and notes taken. The tape recorded interviews were transcribed verbatim and translated from Arabic to English by the investigator. Two interviews which were translated to English were selected and were translated back to Arabic by two other individuals separately. The two interviews which were translated back to Arabic were compared with the original Arabic transcripts and no discrepancies were found between the original and back-translated transcripts.

The data from the interview guide were categorized. The category system was employed for classifying units of content.

A copy of each interview transcript was filed separately for further reference. All the responses to a specific question were written down and filed separately. All the data for a question were examined and the main ideas from responses were identified and reported.

F. Protection of Human Subjects:

The study was a qualitative one in which the participants were asked to answer the interview guide questions. Permission was obtained from the Medical Records Center in Salmaniya Medical Center in Bahrain to review the records and select the sample. The participants were Bahraini adolescents between the age of 13 and 15 years.

The investigator contacted the participants and their parents, explained the study to them, and received their verbal consent to participate. All the participants were informed about the study and were told that they were free to withdraw their participation at any time or not to answer any question. All the interviews were conducted at the participants homes and according to their time convenience.

The confidentiality of the participants and their responses were maintained throughout the study. Only the investigator listened to the tape recorded interviews, which were erased after they were transcribed. No names or addresses were attached to the interview. During the study all the information was stored at the investigator's home, accessible only to the investigator. In addition, the study was approved by the Institutional Review Board of Boston University's School of Nursing and Bahrain's Ministry of Health.

CHAPTER IV

RESULTS

A. Introduction:

In this chapter, the data from the interviews will be analyzed. Content analysis will be used to analyze all the categories that have been stated in the participants' interviews. A description of the study sample will proceed the data analysis.

B. Description of Study Sample:

The participants' age ranged from 13 to 15 years. Two of the participants were 13 years old while five of the participants were 14 years old. The remaining three were 15 years old. There were equal numbers of males and females in the study sample. In Bahrain, at the age of 13 to 15 years, adolescents should have finished at least 9 to 10 years of schooling. The participants' education ranged from 4 to 10 years of schooling. Two of the participants were in primary school. Seven of them were in intermediate school. One was in secondary school. Five of the participants were below the educational levels they were supposed to be in according to their age. All the participants were neither first nor last born in their families.

The ages of the participants' fathers ranged from 34 to 60 years with a mean of 47 years. Their mothers

ranged from 24 to 45 years of age with a mean of 37 years. The participants' fathers' education varied from an inability to read or write to a few years of schooling. One completed 5 years of schooling, and another one 11 years of schooling. Four can read the Holy Quran only. The remaining four can neither read nor write. All the participants' mothers did not have any kind of formal education except for one mother who had finished four years of schooling.

The participants' fathers had different jobs. Five were laborers and two own their own shops. One was a foreman. The remaining two were unemployed and retired. All the mothers were housewives and did not work outside the home.

Six of the parents were related (either first or second cousins). The remaining four parents were not related. The number of children in a family ranged from 4 to 12 children with a mean of 8 children. The family size ranged from 6 to 23 members (nuclear and extended) with a mean of 12 members. The study sample had an equal number of nuclear and extended families. All the participants lived in a house owned by the family. Seven of the participants lived in villages and the remaining three were from the city.

In the study sample, all the families had more than one member who was either sick with sickle cell disease

or carrying the disease. However, the remaining family members were not sure or did not know if they were sick or carriers because they had not had their blood tested. Table I illustrates the occurrence of sickle cell disease in ten families, including the participants.

TABLE I

OCCURRENCE OF SICKLE CELL DISEASE
IN TEN FAMILIES INCLUDING THE PARTICIPANTS

Family No.	Children (Age)		No. of Children Condition Unknown	Parents	
	Carrier	Sick		Father	Mother
1)		d ^a (15) s ^b (9) s* (14)	4	unknown	unknown
2)	s (12) d (15)	s* (13)	9	unknown	unknown
3)	d (17)	s* (15)	2	carrier	unknown
4)	d (19) d (9) s (2)	s (22) s (17) s* (14)	3	carrier	carrier
5)		s (12) s* (14)	10	unknown	unknown
6)	s (25)	d (28) d* (15)	7	unknown	unknown
7)		d (23) s (22) s (20) d* (14)	5	unknown	unknown
8)		s (19) s (14) d* (15)	4	unknown	unknown
9)	d (9)	d* (13) d (8) s (4)	5	carrier	carrier
10)	s (7)	s (16) d* (14) s (11) d (9)	2	unknown	carrier

^a daughter

^b son

* participant in the study

C. Data Analysis:

1. General Information About Sickle Cell Disease:

a. Knowledge of the disease:

The question regarding definition of sickle cell disease was designed specifically to solicit general reactions and/or responses from participants. Responses varied as to the individual's knowledge of the disease. Among the 10 participants involved in the research study, 7 defined sickle cell disease in terms of pain (see the section on pain description). One participant referred to sickle cell disease in terms of loss of function as evidenced by an inability to play football or go outside. One participant reported that it is an ailment related to deficiency in white blood cells. Another participant did not know what sickle cell disease was about and did not have any specific definition for the disease.

The investigator asked all the ten participants how long they had been sick with sickle cell disease. All the 10 stated that the onset of sickle cell disease was during their childhood. Two participants pointed out that they became sick at the age of 2 years. Three others mentioned that they got sickle cell disease when they were 3 years old, and 2 other participants reported that they became sick at the age of 6 years. The

remaining three were not specific.

In response to the question as to what symptoms they experienced when they were sick, all the participants described similar symptoms. The symptoms included pain in joints, especially knees, arms, back and all over the body (cannot move or walk), swollen eyes and a bloody nose. The major complaint was of pain. The degree of pain was described from moderate to severe. During crises of sickle cell disease all the participants stated that they could not walk or move. They had to rest and stay in bed.

When asked what the causes of their disease were, 7 out of 10 participants stated that they did not know the causes of their disease and gave different reasons for it. One participant indicated the cause was hereditary or that it was a contagious disease. Another one said that the cause of her disease was the cold shower and stated that after taking a shower or bath she would get sick. Yet another participant gave a very different cause for disease, She said:

I do not know, nobody told me from what I got it, but my mother said that when I was a child, somebody from the neighborhood hit me. Since then I became sick and had sickle cell disease.

Two participants attributed the causes of their disease to play activity. They stated that they always got sick after playing football, running around and swimming.

One attributed the reason for her disease to eating some kind of beans. Another participant referred to the causes of her disease as less blood. She said, "I have less blood in my body".

Regarding the severity of the disease, all the participants described the pain of sickle cell disease to be very severe. They mentioned that the initial pain was very mild and then increased in severity. The location of the severe pain was in the arms and legs. Some included that with the severity of pain they could not move or walk. One participant said that the crisis of the sickle cell disease differed from time to time in terms of severity. There were times when the pain was mild and other times it was very severe. One participant revealed that the severity of the pain was milder at a younger age, but as he grows, the pain is becoming more severe. In contrast, another participant said that the pain was most severe when she was younger, but as she grew up, the frequency and severity of the attacks lessened.

The duration of sickle cell crisis varied from one participant to the other. For example, two said that the duration of sickle cell crisis was between 4 and 5 days. Three reported the duration to be 4 days to one and half week or more. For two of the participants, the duration was determined by the severity of the attack.

Mild attack lasted just 2 days, while severe attack could last up to 10 days.

In response to the question regarding the knowledge of hereditary of the disease, 6 out of 10 participants mentioned that they did not know that this was hereditary, despite their being told in the hospital.

As one of them stated:

I do not know, may be it is hereditary, because in the hospital they told us it is hereditary.

Another participant said:

I do not know because some of my brothers and sisters have it and the others do not have it.

Three participants stated that they knew that their disease was hereditary. These same three stated that their disease was spread between relatives and was passed from parents to children. As one of them said!

Yes, I know it is hereditary. My father has a sister who has sickle cell disease and I think I got it from her.

One participant was not sure if sickle cell disease was hereditary or not. She said:

I have an idea that it spread between relatives, because my oldest sister and my brother have it, but not all of my sisters and brothers. Also only some family member have it and not all of them.

b. Resource of Knowledge:

When the participants were asked who

explained the disease to them, 8 participants stated that the doctor had explained it to them. They pointed out that doctors were the only professionals who had explained the disease to them. Doctors also had given them other advice, which included drinking plenty of fluid, eating a well-balanced diet, not playing for long periods and taking their "tablets". The participants also mentioned that nobody, including the doctors, had explained to them what sickle cell disease was. They reported that the nurses did not provide any explanation. One participant mentioned that one of her teachers at school had explained the signs, symptoms, and treatment of anemia (not sickle cell disease) and recommended food for treatment. Another participant stated that her sister who has sickle cell disease told her that she had the same disease and would have pain. All the participants mentioned that their parents advised them to drink fluids, to take their tablets, and to eat adequate and balanced diets.

When the participants were asked to whom they talked about their disease, 9 reported that they did not talk to anybody about their disease. They stated that they just told their parents when they felt pain. Some participants stated that while they talked to no one about the disease, they did ask their parents about the reason for their disease and why they had it. As one of

them said:

I just tell my parents when I have the pain, I feel shy to ask the doctor because I am afraid he will not answer me. I also do not like to ask anybody about my disease.

One participant stated that she always talked to friends and family about her disease. She said:

I talk to my friends and family, especially my mother and my sister in law. I always ask them from what I got the disease, why every time I will have it and why my cousins are cured and I am not.

c. Health Maintenance Practices:

When the participants were asked about activities that they did to maintain or decrease the severity of the disease, all the participants stated different activities that they did in order to keep themselves healthy and, therefore, minimizing the occurrences and severity of the disease in an attempt to avoid hospitalization.

The activities that all of the participants stated are:

- Avoiding cold weather by keeping themselves warm.
- Avoiding the air conditioning as much as possible in the summer.
- Avoiding carrying heavy things or doing strenuous things.
- Doing excercises for the whole body, especially legs and arms in order for blood circulation.
- Drinking plenty of fluid.

- Eating vegetables and fruits.
- Resting.
- Massaging the body with olive oil.
- Lastly, taking their tablets perscribed by their doctors.

In response to the question about what activities they did which increased the occurrence and severity of the disease, 7 participants referred to playing. Playing included running, jumping, walking for long periods and football. They stated that always after playing their body would start to hurt, the pain would increase, and then they would be sick. One participant mentioned that he would feel the pain all over his body if he stayed in a cold places. Another participant stated that if she did not take her tablets and played for a period of time, the disease became worse. Another participant mentioned that she did not follow the doctor's advice. She said:

Things that the doctor told me to do,
sometimes I do them, but other times I do
not drink enough fluid and eat well, but
I always like my tablets.

d. Effect of Climate:

With regard to the effect of climate on the severity of the disease, 6 out of 10 participants stated that their sickle cell disease was more severe during the winter when the weather was very cold and rainy.

They stated that they tried to keep themselves warm by wearing warm clothes. Also they stated that even though they felt much better in summer, staying in a place where the air conditioning was on for a long period would effect them. The air conditioning intensified their sickness. Two participants mentioned that the severity of sickle cell disease was greater in summer. They stated that they got sicker after and that it was very severe especially if they played outside when the weather was very hot. With two participants, the different climate did not make any difference in the severity of the disease. As one of them said:

I do not know. In winter it is more when I am sick, I just rest, take my tablets and my mother cover me. In the summer it is the same, if I sit in a room where the air conditioning is on I will have the pain, so the weather do not make any difference.

2. Effect of Sickle Cell Disease on Daily Living:

In response to the question, about how they were being treated at home, all participants stated that they were treated differently from their siblings because they were sick. All of them stated that their parents did not allow them to play freely and play was restricted to indoors with their siblings. With regard to helping in the house, all of them stated that most of the time they were not allowed to help and were asked to rest. If they were allowed some household activity, it was restricted to simple things. The participants

stated that they were not allowed to go outdoors whenever they wanted especially during noontime. This was all because they are sick. As one participant said:

If I am O.K. my mother allows me to play but not as freely as I want because she is afraid I will become sick. She will allow me to help in some of the housework. No, she does not allow me to go out freely and especially in noontime. If I am sick they will not allow me even to move.

When the participants were asked how they were being treated at school, 9 of them reported that they were treated differently from their peers. They stated that the school knew about their disease because the parents had asked the doctors to write a report about their condition. The parents would give these reports to the school personnel. During the physical education activity, all of the 9 participants indicated that the teacher would not allow them to participate in the activity even though their disease was not active at that time. They were always asked to sit and rest. Other school activities were not allowed because the children were told they would tire too easily. All the 9 participants reported that they were frequently absent, as they did not attend school when they were sick. Length of absence was from 4 to 10 days. The participants expressed concern about missing classes and exams during their absence. This, they said, had a

major effect on their studies. These effects included repeating classes, retaking the exams and receiving poor grade averages. Only one participant stated that the school did not know about her disease and that her disease had not affected her study. She said:

I do not feel any difference between me and the other girls. I play in the school. I did not tell the teacher that I am sick or have a disease, so she will allow me to play like other girls. My studies are the same. My disease is not affecting me because I have never been absent from school, so my study will not be affected. Sometimes I feel the other girls are healthier than me.

In response to the question, concerning how they felt about the way they were being treated, all of the participants stated that they got very upset, angry and depressed. They stated that being treated differently from other peers had affected them. They felt that they were restricted in their play and were different from children of the same age. As one of them said:

It makes me very upset and angry because I cannot play or go out as freely as I want.

Another participant said:

I feel really upset, angry and depressed because I am not allowed to do anything as freely as I want and this is all because of the disease that I have.

3. Effects of Sickle Cell Disease on Future Plans and Decisions:

When the participants were asked about their future life plans and decisions concerning their

education, 4 of them stated that they would select the sciences, they mentioned that they liked this field and they were given the freedom to choose the field they liked. Two out of the four mentioned above indicated that they knew their disease would effect their future study. However, the other two stated that their disease would not effect their future study, because they thought they would be better when they grew up. Two of the participants stated that they would choose the easiest and simplest field. They would choose the easy field because they thought that the disease would effect their study, so it was better to choose a simple field. Four of the participants mentioned that they did not decide what they would be studying. Because they were always sick, so they did not know what to choose. As one participant said:

I did not decide what I will do after high school, but I like to be a biology teacher. Yes, my disease will effect my study. I always think about it, so that is why I do not want to study more after high school.

Regarding the work that they would like to do after finishing school, the participants gave different responses. Four of them reported that they would choose the jobs they liked. They stated that the disease would not effect their work. They thought their disease would be much milder when they grew up. Five of the

participants mentioned that they had not decided yet, but stated that they would look for an easy job that did not require much physical activity. They reported that they not only knew that their disease would effect their jobs, but also they thought they might be fired from their jobs for being sick and absent. One participant stated that she would like to be an air hostess because she thought she would be cured when she grew up. She mentioned that her niece who had the same disease was cured when she grew up.

Regarding marriage, all of the participants indicated that they were not sure about what age they would marry. All of the participants mentioned that they wanted to marry somebody who did not have sickle cell disease. They stated that they were afraid their disease would pass to their children especially if the other partner had the same disease. When they were asked about marriage to a relative, all of them stated that they would marry a relative if he or she did not have sickle cell disease. They mentioned that they knew their disease might pass to their children but not necessarily between relatives. As one of them said:

First, I want him to check his blood and see if it suit my blood. Secondly, he should not be from my relatives because it will effect the children. But if he is my cousin and his blood suit mine and does not have sickle cell disease, I will marry him. I do not think it will effect the children if he is from my relatives

and does not have the same disease.

With regard to number of children, all of the participants stated that they wanted a minimum number of children (2-3). They indicated that the more children they had, the greater the possibility of having sickle cell disease.

At the end of the interview all the participants were asked if they thought they would be better or cured when they grew up. Five of them stated that they thought they would be cured and the disease would disappear. This was because some of their family members who had had the same disease were cured when they grew up. Also, their parents told them that they would be cured when they grew up. They did not know if there was a treatment for their disease, but they were sure they would be cured. Three of the participants stated that they knew they would not be cured. But they had the hope to become much better. They stated that if they had a good diet, plenty of fluids and their tablets, they might grow up stronger. Then they could fight the disease and be much better. One participant stated that he did not know if he would be better or not. Another participant stated that the disease may become more severe when she grew up because her oldest sister had the same disease and it got more severe when she grew up.

CHAPTER V

DISCUSSION AND RECOMMENDATIONS

A. Introduction:

In this chapter, each category that has been analyzed in the previous chapter will be discussed and followed by recommendations for further research, practice and education.

B. Discussion:

1. General Information About Sickle Cell Disease:

a. Knowledge of the disease:

From analysis of the data in the previous chapter, none of the participants could define sickle cell disease in a simple form by definition of the term. All of them defined the disease in terms of symptoms, like pain or loss of function, which most if not all felt during sickle cell crisis. They described the symptoms but not what the disease was. By the participants' definition, it can be deduced that all of them are ignorant of what sickle cell disease is, that is the pathology and inherited aspects of it.

Regarding the onset of sickle cell disease, none of the participants stated that they had been born with the disease. All of them stated that they got it in their childhood. This indicated that they do not know that sickle cell disease is a genetic disease which they were

born with.

All the participants described similar symptoms that they experienced during their crisis. They emphasized pain as a major complaint and the degree of pain varied with each participant. These symptoms are consistent with the symptoms of sickle cell disease described in medical literature.

Most of the participants did not know what the causes of their disease were. Some of them gave the precipitating factors or the factors that influence the disease as the cause. These included playing, taking cold showers and having less blood in their bodies. However, the other participants gave extremely different causes for their disease, causes which had been told to them by their parents.

As one participant said:

I do not know, nobody told me from what I got it, but my mother said that when I was a child somebody from the neighborhood hit me. Since then I became sick and had sickle cell disease.

All the participants stated that pain was very severe even though the severity might be different from time to time. However, some of the participants indicated they were better when they were younger, while others indicated that they were much better now. Duration of the crisis as it was reported by the participants lasted from 3-10 days.

Some of the participants did not know that their disease was a hereditary disease even though they had been told in the hospital. This indicates that the information given to them may have been insufficient or unclear or they did not remember being told. The remaining participants mentioned that they knew their disease was hereditary. But they were not sure what hereditary meant exactly. This again illustrates that information given to them was inadequate or generalized.

From all the previous discussion, we can conclude that these adolescents who have sickle cell disease lack the necessary knowledge about their disease. This also indicates that these adolescents need to be provided with sufficient information and knowledge about sickle cell disease.

b. Resource of Knowledge

From the data analysis on who explained the disease to them, it is indicated that doctors were the only professionals who explained the disease to them. The explanation included some information about sickle cell disease and pieces of advice like drinking plenty of fluids, eating a well-balanced diet and taking their "tablets". The data also illustrated that neither the nurses nor the school had any role in explaining sickle cell disease. This indicates that Health Care providers are not providing adequate information about sickle cell

disease to these adolescents. The school, where these adolescents spend a good part of their lives don't have a role in explaining such information. Parents also do not have an effective role in explaining about sickle cell disease to thier children.

When asked to whom they talked about their disease, nine participants indicated that they did not talk to anybody about their disease, except for one participant who stated that she usually talked to her family about her disease. The participants mentioned that they did not ask the doctors questions regarding sickle cell disease because they were afraid the doctor might not answer them. This indicates that these adolescents who suffer from a chronic illness like sickle cell disease are not being encouraged by health care providers, the school, or their parents to open up, talk, ask or seek information about their disease.

c. Health Maintenance Practices:

All the participants stated that they did different activities in order to maintain or decrease the severity of the disease. They also mentioned that they usually did activities like doing excercises, avoiding air conditioning, and drinking plenty of fluids to try to avoid rushing to the hospital. These activities seem to help the adolescents maintain their health. Within certain limitations, these activities

are useful practices, so health care providers as well as the parents could reinforce the practice of these activities.

All the participants in the study sample stated some of the activities that they did which usually increased the occurrence and severity of the disease. These activities included playing for a long period, staying in a room where the air conditioning was on for a long time, not taking their "tablets" and not following the doctors order. We can conclude that the adolescents do not know the necessity of avoiding the activities which increase the severity of sickle cell disease. Health care providers as well as parents could emphasize the necessity of playing to their own individual level of tolerance. They could also reinforce the necessity of taking their tablets and following the doctors advice.

d. Effect of Climate:

Studies show that there is a climate effect on sickle cell disease. Rozzell et al (1983) stated that patients frequently cite abrupt weather changes as a cause of crises. This factor most likely is caused by an increase in venous stasis in the extremities in cold weather which increases sickling activity. In Bahrain the weather is cold in the winter. In the summer, it is very hot and people constantly use the air conditioning

(A/C). In the summer, people spend most of the time in cool places where the air conditioning is on. The cooling of A/C has the same effect as the winter weather.

In the study sample, the majority indicated that the disease was more severe in the winter, which is consistent with the studies done on effect of cold weather on sickle cell disease. However, the remaining participants indicated that sickle cell disease was more severe in the summer, and this is due to the use of A/C. From this discussion, we also can conclude the necessity of always keeping themselves warm, so these adolescents should always be instructed and reinforced to wear warm clothes and try to avoid the cold weather.

2. Effect of Sickle Cell Disease on Daily Living:

All the participants stated that they were treated differently from their siblings at home. They mentioned that they were not allowed to play freely, go out as much as they liked and that they were allowed to help out with very simple things at home. They felt that this was the result of being sick and also their parent's being over-protective. Adolescents is not only a stage of rapid growth when reproductive organs begin to mature, but it is a stage of developing identity and independence as well. Many parents fear the consequence of sickle cell disease. Parents should understand the

needs of independence in this stage, as well as the necessity of not treating the adolescent as a sick person. Adolescents should be encouraged to do as much as they are capable of doing. They should be allowed to associate with peers, play outdoors and help in the household duties, which will make them feel like a productive member of the family.

The participants stated that they were treated differently from their peers in school activities. They were always asked to sit and rest because they were sick and got tired quickly, especially in physical education classes. They also mentioned of being absent from school for a long period of time when they were sick, which effected their academic achievement. This leads them to fall behind at school and even fail the grade. Adolescents spend a significant part of their life in school. Adolescents with sickle cell disease should be encouraged to develop their abilities and to participate to their own level of tolerance in all activities in school. For example, in the physical education class, they can ride bicycles, play kick ball and run. The adolescent should be the judge of his own tolerance and should be allowed frequent rest periods if he desires.

Absenteeism for chronically ill patients like sickle cell patients is a big problem as it effects

academic achievement. For this reason adolescents might need tutorial help during extended hospitalization. Also, these adolescents should be encouraged to try to keep up with their studies.

All the participants stated that they felt very upset, angry and depressed about being restricted and treated differently from their siblings and peers. Adolescents with sickle cell disease may experience particular feelings of fear, anxiety, anger and depression. Depression may effect the adolescents ability to manage his disease and cause him to do poorly socially and academically. Adolescents with sickle cell disease need to be helped in coping with their disease and feelings through counseling, listening, understanding, explaining and not treating them as sick. We can help these adolescents overcome their feeling and live a normal life.

3. Effect of Sickle Cell Disease on Future Plans and Decisions:

The participants in the study had mixed ideas and plans about the kind of field they would like to study in the future. Some indicated that they would choose the field they liked, but still were afraid of the effect of sickle cell disease on their future plans. However, the others stated that they would choose the easiest which did not require much study since they

would always be sick. All the participants stated that their parents had given them total freedom in choosing their future education. Choosing a future education is a major decision and chronic illness like sickle cell disease has an effect on the person's decision. All adolescents with chronic illness and especially sickle cell disease need guidance in setting educational goals and choosing the appropriate educational field suitable for their abilities.

All the participants had different responses with regard to the kinds of jobs they would like to do in the future. Some participants stated that they would choose a job they liked because they thought they would be healthier when they grew up. Others had not decided but stated that they would prefer an easy job which did not require much physical activity.

All adolescents, in general, have their own fantasies of the kinds of jobs they would like to do in the future. Having a chronic illness like sickle cell disease would effect their dreams and fantasies regarding their future job. All adolescents with sickle cell disease need guidance in setting their career goals. Jobs requiring heavy manual labor are usually closed to a person with sickle cell disease. With proper guidance and professional counseling, an exciting and rewarding career can be realized.

All the participants emphasized an interest in marrying a person who does not have sickle cell disease because they did not want sickle cell disease to be passed to their children. When the participants were asked about marriage to a relative, all of them did not mind marrying relatives, as long as the partner did not have sickle cell disease. However, the participants preferred to have a minimum number of children (2-3). They believed that the more children they had, the greater the possibility of these children having sickle cell disease. From the discussion, it seems that the participants do not have the adequate information about heredity, spread of sickle cell disease between relatives, and the effect of marriage to a relative on children.

When they were asked if they would be better or cured when they grew up, all the participants gave different responses and feelings. Some stated that they would be "cured" when they grew up while the others mentioned that they knew they would not be cured but hoped that they would be much better. Chronic illness like sickle cell disease is a life long disease. Patients with sickle cell disease may feel better if they take good care of themselves but will not be cured. These adolescents should be provided with the necessary information about sickle cell disease. This information

would be of a great help to the adolescent who is starting his future life. This information might help him in planning his life appropriately.

C. Recommendations:

The following are recommendations for further research, practice and education.

1. Recommendations for further research:

a. This study should be replicated with a larger number of subjects, different age range and other stages of development.

b. Different aspects in relation to sickle cell disease could be studied such as:

1. Self image in children.

2. Children's adaptability within different environmental settings.

3. Children's coping.

c. Coping with sickle cell disease in Bahraini families.

d. Length of hospitalization for sickle cell disease patients.

e. The effect of hospitalization on developmental stages:

1. 0-3 Toddler

2. 3-6 Pre school

3. 6-12 School age

4. 12-18 Adolescent

f. Nurses' role in caring for patients with sickle cell disease.

g. Follow up research with the same participants during adulthood to determine changes in their perception of sickle cell disease.

2. Recommendations for Practice and Education:

a. Medical professional personnel should provide both implicit and explicit information to patients with sickle cell disease.

b. Medical professional personnel should spend more time with adolescents to provide information and encourage them to ask and talk about their feelings, ideas and knowledge regarding sickle cell disease.

c. A special health education program about sickle cell disease should be developed and implemented exclusively for children with sickle cell disease.

d. The media should be intensively and extensively used by public health service for dissemination of information regarding the disease, from its causes to how it can be avoided.

e. In service education sessions should be planned and implemented for Bahraini and non Bahraini nurses and para medical, so that they could be more involved in the explanation and care processes of sickle cell disease to the patients and their families.

f. An instructional unit dealing with sickle

cell disease and all its aspects should be designed and incorporated into the nursing curriculum of the College of Health Sciences. This would provide the future generation of professional nurses with adequate information and knowledge about sickle cell disease.

APPENDICES

Appendix A
Informed Consent

Boston University School of Nursing
Department of Parent-Child Nursing
635 Commonwealth Avenue
Boston, Massachusetts 02215
(617) 353-4064

A Study of How Adolescents in Bahrain with Sickles
Cell Disease Perceive Their Disease

In a developing country like Bahrain, research is rapidly developing. At this stage of development, subjects for research give oral consent only. It is very difficult to ask parents to sign a consent form because they will think that this is a very formal subject and might refuse to allow their child to participate. For the purpose of explaining and getting parental permission to allow their child to participate, the investigator will read over the telephone the following to all the participants and their parents:

Participant's and Parental Consent Form

I am Fatema Jamali, a faculty member in the College of Health Sciences and a Master Student in the School of Nursing at Boston University. As part of the requirements for my degree, I will be doing research to find out what the adolescent's perceptions about sickles

Appendix A (cont.)

cell disease are. I would like your permission to talk to your child. This information could help us to plan health education programs which are better suited to the needs of the adolescent and which may help them to more easily understand and adapt to their disease. I will do this by talking with 10-14 adolescents individually and asking them to tell me what their perceptions about sickle cell disease are. The adolescent will be allowed to talk for as long as they like although it is expected that the interview will range from 45 to 60 minutes in length. These interviews will be tape recorded. Your child may end the interview at any time, may decide at any time not to participate in the study, and may listen to the tape recording at the end of the interview. Your child may request that parts or all the interview be erased. I will listen to the tapes and write down all the information given by your child. The interview will take place in your home, at a time which is convenient for you and your child. During the interview just your child and I will be in the room, but I will tell your child that he/she is free to call you in at any time. Your child's confidentiality will be respected at all times. Your child will not be identified by name at any time during or after the project. The interview will be coded and only I will know the code. The tape recording

Appendix A (cont.)

will be written down and the original tapes will be erased. I will be the only person who will see the information from your child. There are no risks to your child if you agree to allow him/her to participate in the project. There are no immediate benefits, although this work might help us to plan better health education programs for children with sickle cell disease. There is also no risk if you decide not to allow your child to participate in this study. At any time during or after the study you and your child are welcome to call me and ask questions or request information. Thank you very much for your help and for allowing your child to participate in this study.

Appendix B

INTERVIEW GUIDE (ENGLISH TRANSLATION)

I- General information about sickle cell disease:

A- Tell me, what do you know about sickle cell disease?

Probe For:

- 1- Awareness of having sickle cell disease.
- 2- How long you have been sick.
- 3- Symptoms of the disease.
- 4- Causes of the disease.
- 5- Severity of the disease.
- 6- Duration of the disease.
- 7- The way you got the disease.
- 8- Knowledge about the hereditary of the disease.

B- Now, can you tell me, what do you do to keep yourself healthy?

- 1- Activity you do to maintain or decrease the severity of the disease.

Probe for:

- 1- Seek medical help.
- 2- Take analgesic at home.
- 3- Do excercises.
- 4- Eat proper diet.
- 5- Drink plenty of fluid.
- 6- Effect of the climate:
 - a- In Summer.
 - b- In Winter.

Appendix B (cont.)

INTERVIEW GUIDE (ENGLISH TRANSLATION)

2- Activities you do that increase the occurrence of the disease.

- Play outside too long.
- Have difficulty to comply with the advice and treatment.

C- Can you tell me, who explained the disease to you?

Probe for:

1- Family member:

- a- Father
- b- Mother
- c- Sibling
- d- Other relatives (e.g, Uncle, aunt, etc....)

2- Doctors and Nurses.

3- School teacher.

4- Friends or peers.

5- Reading articles or books.

D- To whom do you talk about your disease?

Probe for:

1- Family member:

- a- Father
- b- Mother
- c- Sibling
- d- Other relatives (e.g, Uncle, aunt, etc....)

2- Doctors and Nurses.

Appendix B (cont.)

INTERVIEW GUIDE (ENGLISH TRANSLATION)

3- School teacher.

4- Friends or peers.

II- Effects of Sickle cell disease on daily living:

A- How are you treated at home?

Probe for:

1- Allowed to play freely.

2- Allowed to play with siblings.

3- Allowed to help in household duties.

4- Free to go out.

5- Free to do other things.

6- Limited to certain activities due to illness.

B- How are you treated at school?

Probe for:

1-School awareness of disease?

2- Allowed to play freely.

3- Allowed to play with peers.

4- Involved in different school activities.

5- Effect of disease on studies and how .

C- Tell me, how do you feel about the way you are treated?

Probe for:

1- Get angry sometimes.

2- Accept the limitation I have.

3- Happy that they are thought of by others.

Appendix B (cont.)

INTERVIEW GUIDE (ENGLISH TRANSLATION)

III- Effects of Sickle cell disease on future plans and decision:

A- How does the disease effect your future plans and decisions concerning education?

Probe for:

- 1- Selection of the field of study.
- 2- Reasons for such selection.
- 3- Effect of disease on selection.
- 4- Influence of others on decision in choosing field? If so, the name of the person?

B- How does the disease effect your future plans and decisions concerning work?

Probe for:

- 1- Type of work participants are interested in after the completion of your studies.
- 2- Reason for choice of type of work.
- 3- Effect of disease on choice of work.

C- Tell me, how does the disease effect your future plans and decisions concerning marriage life?

Probe for:

- 1- The age at which participants are planning to marry.
- 2- Specifications of future husband/wife and reasons for such specifications.
- 3- Intention to marry a relative.
- 4- Number of children planned and why?

Appendix B (cont.)

INTERVIEW GUIDE (ARABIC TRANSLATION)

دليل المقابلة

(١) معلومات عامة عن مرض فقر الدم المنجلي :

أ - ماذا تعرف/ تعرفى عن مرض فقر الدم المنجلي ؟

تحقق بدقة من (تأكد بالتفصيل من):

- (١) العلم بالاصابة بمرض فقر الدم المنجلي.
- (٢) منذ متى أصبت بالمرض.
- (٣) أعراض المرض.
- (٤) أسباب المرض.
- (٥) مدى حدة المرض.
- (٦) مدة المرض.
- (٧) كيفية اصابتك بالمرض.
- (٨) علمك بقابلية توارث المرض.

ب - هلا أخبرتنى عما ماغعله للمحافظة على صحتك ؟

أ - النشاط الذى تمارسه لوقف حدة المرض أو الحد منه.

تحقق بدقة من (تأكد بالتفصيل من):

- (١) تطلب المساعدة الطبية.
- (٢) تناول السكن فى المنزل.
- (٣) تعمل تمارين رياضية .
- (٤) تناول غذاء خاص.
- (٥) تشرب سوائل كثيرة.
- (٦) تأثير المناخ :

أ - فى الصيف.

ب - فى الشتاء.

ب - النشاطات التى تقوم بها والتى تزيد من حدوث (تفاقم) المرض (ازدياد حدة المرض).

- تلعب كثيرا خارج المنزل.

- تواجه صعوبة فى الالتزام بشورة الطبيب والعلاج اللازم.

ج - من الذى قام بتوضيح المرض لك؟

Appendix B (cont.)

INTERVIEW GUIDE (ARABIC TRANSLATION)

تحقق بدقة من (تأكد بالتفصيل من) :

- ١- أحد أفراد العائلة :
 - أ - والدك.
 - ب - والدتك.
 - ج - أخوتك وأخواتك.
 - د - شخص آخر من الأقرباء (مثلا : عمك أو عمتك ، خالك أو خالتك...)
- ٢- الأطباء والمرضات/ الممرضين.
- ٣- مدرسي المدرسة.
- ٤- أصدقائك أو زملائك.
- ٥- من خلال قراءتك للمقالات أو الكتب.
- ٥- الى من تتحدث عن مرضك ؟

تحقق بدقة من (تأكد بالتفصيل من):

- ١ - أحد أفراد العائلة :
 - أ - والدك
 - ب - والدتك
 - ج - أخوتك وأخواتك
 - د - شخص آخر من الأقرباء (مثلا : عمك ، أو عمتك ، خالك ، أو خالتك ...)
- ٢ - الأطباء والمرضات/الممرضين.
- ٣ - مدرس المدرسة.
- ٤ - اصدقائك أو زملائك.

(٢) آثار مرض فقر الدم المنجلي على حياة المريض اليومية:

- أ - كيف تعامل في المنزل ؟

تحقق بدقة من (تأكد بالتفصيل من):

- ١ - يسمح لك باللعب بحرية تامة.
- ٢ - يسمح لك باللعب مع اخوتك.
- ٣ - يسمح لك بالمساعدة في أعمال المنزل
- ٤ - يسمح لك بالخروج من المنزل
- ٥ - يسمح لك بعمل أشياء أخرى.
- ٦ - ملزم بإداء نشاطات محددة لكونك مريض.

Appendix B (cont.)

INTERVIEW GUIDE (ARABIC TRANSLATION)

ب - كيف تعامل في العرسة ؟

تحقق بدقة من (تأكد بالتفصيل من):

- ١ - هل درستك تعلم بمرضك؟
- ٢ - يسمح لك باللعب بحرية تامة؟
- ٣ - يسمح لك باللعب مع زملائك؟
- ٤ - تتم مشاركتك في نشاطات مدرسية مختلفة.
- ٥ - هل يؤثر المرض على تحصيلك العلى ؟ اذا كانت الاجابة بنعم فمن أى ناحية ؟

ج - ماهو شعورك تجاه الطريقة التى تعامل بها ؟

تحقق بدقة من (تأكد بالتفصيل من)

- ١ - أغضب أحيانا .
- ٢ - أقبل بالحدود التى تسمح لى بذلك .
- ٣ - سعيد لكون الناس يفكرون بى .

(٣) آثار مرض فقر الدم المنجلي على الخطط والقرارات المستقبلية للمريض :

أ . كيف يؤثر المرض على خططك وقراراتك المستقبلية فيما يتعلق بالتعليم .

تحقق بدقة من (تأكد بالتفصيل من):

- ١- اختيار مجال الدراسة .
- ٢- سبب هذا الاختيار .
- ٣- هل يؤثر مرضك على اختيارك هذا .
- ٤- هل أثر أحد ما على قرارك بأختيار مجال دراستك ؟ اذا كانت الاجابة بنعم من هو ذلك الشخص ؟

ب . كيف يؤثر المرض على خططك وقراراتك المستقبلية المتعلقة بالعمل ؟

تحقق بدقة من (تأكد بالتفصيل من) :

- ١ - نوعية العمل الذى ترغب فيه بعد اكمال دراستك .
- ٢ - سبب اختيارك لهذا النوع من العمل .
- ٣ - هل يؤثر مرضك على اختيارك للعمل .

Appendix B (cont.)

INTERVIEW GUIDE (ARABIC TRANSLATION)

ج. كيف يؤثر المرض على خططك وقراراتك المستقبلية المتعلقة بحياتك الزوجية.

تحقق بدقة من (تأكد بالتفصيل من):

- ١ - متى تنوي الزواج ؟
- ٢ - المواصفات التي تتوفر في زوجتك في المستقبل - سبب ضرورة توفر هذه المواصفات.
- ٣ - هل ستكون (زوجتك) واحدة من أقاربك ؟
- ٤ - كم طفلا تنوي أن يكون لديك . ولماذا ؟

Appendix C

INTERVIEW FACE SHEET (ENGLISH TRANSLATION)

Date: / /

Code:

I- Interviewee:

a- Age

b- Sex: M/F

c- Education:

Do you Read and Write?

Yes

No

(Circle the year of schooling)

Primary 01 02 03 04 05 06

Intermediate 07 08 09

Secondary 10 11 12

d- What is your order in the family among
children?II- Interviewee's Father:

a- Age

b- Education:

Does your Father Read and Write?

Yes

No

(Circle the years of schooling)

Primary 01 02 03 04 05 06

Intermediate 07 08 09

Appendix C (cont.)

INTERVIEW FACE SHEET (ENGLISH TRANSLATION)

Secondary 10 11 12

Undergraduate 13 14 15 16

Graduate: Master's 17 18

P.H.D. 19 20 21 22

c- Work

III- Interviewee's Mother

a- Age

b- Education:

Does your Father Read and Write?

Yes

No

(Circle the years of schooling)

Primary 01 02 03 04 05 06

Intermediate 07 08 09

Secondary 10 11 12

Undergraduate 13 14 15 16

Graduate: Master's 17 18

P.H.D. 19 20 21 22

c- Work

IV- Are you and your husband related?

Yes In which way?

No

V- No of children.

Appendix C (cont.)

INTERVIEW FACE SHEET (ENGLISH TRANSLATION)

VI- Family Size.

VII- Family Structure.

VIII- Residence type and place.

IX- No. of persons sick with sickle cell or carrying the

Person	Age	Sex		Carrier	Sick
		M	F		

Appendix C (cont.)

INTERVIEW FACE SHEET (ARABIC TRANSLATION)

الورقة الأمامية للقاء

الرقم (الرمز):

التاريخ: / /

١- الشخص الذي تمت معه القابلة :-

أ - السن

ب - الجنس: نكر/ أنثى

ج - التعليم :

هل تجيد القراءة والكتابة؟

نعم ٠٠٠٠

لا ٠٠٠٠

(ضع دائرة حول سنوات الدراسة)

٠٥	٠٤	٠٣	٠٢	٠١	المرحلة الابتدائية
		٠٩	٠٨	٠٧	المرحلة الإعدادية
		٠١٢	٠١١	٠١٠	المرحلة الثانوية

د - ماهو ترتيبك في السن بين اخوتك ؟

٢- والد الشخص الذي تمت معه القابلة :

أ - السن

ب - التعليم

هل يجيد والدك القراءة والكتابة ؟

نعم ٠٠٠٠

لا ٠٠٠٠

Appendix C (cont.)

INTERVIEW FACE SHEET (ARABIC TRANSLATION)

(ضع دائرة حول سنوات الدراسة)

٠٦	٠٥	٠٤	٠٣	٠٢	٠١	المرحلة الابتدائية
			٠٩	٠٨	٠٧	المرحلة الإعدادية
			٠١٢	٠١١	٠١٠	المرحلة الثانوية
		٠١٦	٠١٥	٠١٤	٠١٣	المرحلة الجامعية (البكالوريا)
			٠١٨	٠١٧		مرحلة الدراسات العليا ماجستير
		٠٢٢	٠٢١	٠٢٠	٠١٩	الدكتوراه

ج. العمل.

٣- والدة الشخص الذي تمت معه المقابلة :

أ - السن

ب - التعليم

هل تجيد والبطك القراءة والكتابة ؟

نعم

لا

(ضع دائرة حول سنوات الدراسة)

٠٦	٠٥	٠٤	٠٣	٠٢	٠١	المرحلة الابتدائية
			٠٩	٠٨	٠٧	المرحلة الإعدادية
			٠١٢	٠١١	٠١٠	المرحلة الثانوية
		٠١٦	٠١٥	٠١٤	٠١٣	المرحلة الجامعية (البكالوريا)
			٠١٨	٠١٧		مرحلة الدراسات العليا : ماجستير
		٠٢٢	٠٢١	٠٢٠	٠١٩	الدكتوراه

ج - العمل.

Appendix C (cont.)

INTERVIEW FACE SHEET (ARABIC TRANSLATION)

۴۔ هل أنت وزوجتك/زوجك على قرابة (قبل زواجكما)؟

... نعم

... y

إذا كانت الإجابة بنعم حدد صلة القرابة.

٥ - عدد الأطفال.

٦ - حجم العائلة (الاسرة) .

٧ - تركيب العائلة.

٨ - نوع ومكان السكن.

٩ - عدد أفراد العائلة المصابين بمرض فقر الدم المنجلي والحاطين له:

الشخص	السن	الجنس	حامل المرض	مصاب بالمرض
		نكر	أنثى	

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