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# Saudi Arabian mothers of children with sickle cell disease as givers of social support

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SAUDI ARABIAN MOTHERS OF CHILDREN WITH SICKLE CELL DISEASE AS  
GIVERS OF SOCIAL SUPPORT

An Abstract of a Thesis  
Submitted  
in Partial Fulfillment  
of the Requirements for the Degree  
Master of Arts

Fatimah Sameer Alrubh  
University of Northern Iowa  
December 2016

## ABSTRACT

The purpose of this study is to understand the perceptions of mothers in the Eastern Province of Saudi Arabia, in Qatif City when using four social support types (emotional support, instrumental support, informational support, and appraisal support) with their children who have Sickle Cell Disease (SCD). Also, this study aims to understand the mothers' roles in providing social support to children with SCD, as well as assess the types of social support that mothers used to help their children with SCD. Lastly, this study assesses the factors that influence the mothers to provide social support. A qualitative design; semi-structured interview method was used. Interview questions were created in both Arabic and English, but, the participants were interviewed in Arabic. Results suggest that most mothers of children with SCD use instrumental and emotional support the most, followed by informational support. No evidence of appraisal support was reported by mothers in this study. In addition, there are some factors that affect Saudi Arabian mothers providing social support to their children with SCD, such as belief in God willing, the role of extended family, and the roles of role model and beauty concept. Finally, at the end of the study, the mothers indicate positive perceptions of use of social support.

*Keywords:* Sickle cell disease, social support, children and adolescents, physical health, mental health.

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This Study by: Fatimah Sameer Alrubh

Entitled: Saudi Arabian Mothers of Children with Sickle Cell Disease as Givers of Social Support

has been approved as meeting the thesis requirement for the

Degree of Master of Arts

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## DEDICATION

*I humbly dedicate this thesis:*

*To my dearest parents, Sameer and Ruqia, thanks for the wise counsel you provided to me. I was trying my best to achieve your, my dreams, and to be a successful person that you will always be proud of. You are always in my mind and heart.*

*To my lovely husband, Mohammed, who stood by me. I cannot express my gratitude to you. I know it was hard to be far from me especially during my thesis defense, but, I still get the benefits from your warm suggestions, advice, and love that you provided to me. Thanks very much my lovely 'advisor' and 'husband' for all of your supportive words and help.*

*To my lovely twin girls Sarah and Ayaa. I know it was hard for all three of us to miss daddy, but, finally we made it. I started my graduate school with you and I can't imagine my life without you. We passed all the challenges that we faced together and I am sure we will pass the future challenges together as well. Thanks for your smiles and keep smiling every day to give me strength. I am really enjoying my life with you.*

*To my dear sister Zainab, you are really a great model of a supportive sister and auntie. Thanks for being patient with me and my twins. I know it was hard to be a good college student while providing warm support for me. Thanks for everything you have done and you will do for me*

*To my other sisters and brothers who live back home in Saudi Arabia, Manar,*

*Boshra, Ali, and Mohamed, as the oldest sister, I hope that I have been a good example and model for you to achieve success.*

*To my friends, this thesis would not have been possible without you. I know many of you are proud of me and happy for my success. I would like to thank you for sympathetic ear, support, and help.*

*To everyone else who always believed in me and has supported me throughout my life.*

*Love you all*



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## CHAPTER I

### INTRODUCTION

Sickle cell disease (SCD) is a genetic blood disorder characterized by the production of the abnormal hemoglobin S. As a genetic disorder, SCD is one of the most common and severe monogenic disorders in the world. SCD often affects one's quality of life and is associated with morbidity and a decreased life span. Furthermore, hospital-based studies from the Eastern Province of Saudi Arabia reported that 73% of deaths due to SCD occur to individuals under 30 years of age (Jastaniah, 2011). Individuals with SCD are at higher risk to experience emotional distress, physical dysfunction, and poor mental and social health (McClish et al., 2005).

Although SCD is a worldwide disorder, it is more likely to be found in specific areas of the world and among some locations versus others. For example, SCD is common within some areas in Africa (Senegal, Benin, Bantu, and Cameroon) and among Middle Eastern and Indian people. In Africa, annually, there are more 200,000 infants born with SCD (Jastaniah, 2011) and globally there are more than 230,000 children born every year with SCD (Rees, William & Gladwin, 2010). Also, 1 in 365 African Americans in the US lives with SCD (Jenerette & Brewer, 2010). SCD is also commonly found among Hispanics from the Caribbean, Central America, and parts of South America (Gold, Treadwell, Weissman, & Vichinsky, 2008).

Many studies report that SCD is a major genetic disorder in Saudi Arabia. Since the 1960s, there has been high prevalence of SCD cases in Saudi Arabia (Jastaniah, 2011). Jastaniah (2011) conducted a study in Saudi Arabia to determine the prevalence of

SCD among children and adolescents. The results showed that SCD was distributed in the Eastern Province with a prevalence of 145 per 10,000 residents, whereas, the Southern region has a prevalence of 24 per 10,000 and in the Western Province the prevalence of SCD was 12 per 10,000 people, and 6 per 10,000 (the central region) (Al-Qurashi, El-Mouzan, Al-Herbish, Al-Salloum, & Al-Omar, 2008). Recent statistics showed that SCD affects: 17.0% of people in Qatif (Eastern Region), 10.3% in Gizan (Southern Region), 18.1% in Ula (Northern Region) and 2.5% in Mecca (Western Region) (Amr, Amin, & Al-Omair, 2011). However, Eastern Province has the highest rate of SCD in Saudi Arabia based on neonatal screening. The neonatal screening results showed that 29,246 infants in Qatif City in Eastern Province are born with SCD, 99.5 per 10,000 infants were born with SCD in Dammam Central Hospital and in Al-Khobar Teaching Hospital in Eastern Province (Al-Qurashi et al., 2008). Because SCD has no cure, appropriate social support can provide a means by which a family can receive assistance to care for family members with SCD.

### Social Support and Family Role

Since the 1970s, social support has proven to be a major method of treatment and intervention that strongly affects health and well-being (Cohen & Syme, 1985). Research shows that a lack of social support is linked to poor physical and mental health and in some cases it is linked to death (House, Landis, & Umberson, 1988). Social support works as a buffer to stress and is linked to improved physical health (House et al., 1988).

In addition, Glanz, Rimer, and Lewis (2002, p. 186) categorized social support into four supportive behaviors types. These types are as follows:

- (a) Emotional support involves the provision of empathy, love, trust, and caring.
- (b) Instrumental support involves the provision of tangible aid and services that directly assist in person in need.
- (c) Informational support involves the provision of advice, suggestions, and information that a person can use to address the problem.
- (d) Appraisal support involves the provision of information that is useful for self-evaluation purposes, in other words, constructive feedback, affirmation, and social comparison.

Under the umbrella of social support, these social support types tie together to lead to overall positive results in the health status of individuals with SCD.

Parents of individuals with SCD report being distressed and anxious about their loved ones' health (Vaughn et al., 2011). Some mothers focus on providing medicine; such as using over-the counter pain relief medication to decrease pain related to SCD. However, individuals with SCD are not only in need of receiving medical care. They are in a higher need of receiving social support (Atkin & Ahmed, 2000). Furthermore, Vaughn et al. (2011) found that the family has an essential role in providing social support. Specifically, mothers habitually take the primary responsibility to provide

counseling, guidance, and support regarding the health needs of members with SCD (Vaughn et al., 2011).

Because individuals with SCD have poor overall wellbeing-psychological, physical, and social (Palermo, Schwartz, Drotar, & McGowan, 2002), social support is one of the effective coping mechanisms for individuals with SCD (Vaughn et al., 2011). Social support provided by a family is necessary for individuals with SCD, not only to help them to cope, but also to improve their quality of life (Atkin & Ahmed, 2000). The needs for social support for children with SCD are important, especially for those who are challenged to cope with pain episodes and hospitalizations (Gold et al., 2008). Optimizing care and daily management of SCD is one of the results of utilizing social connections within a family who has a member with SCD. Further, social support has a great impact on increased self-efficiency correlated to pain management (Chen, Cole & Kato, 2004).

#### Statement of the Problem

Sickle cell disease is considered a stressful life-event. Both children with SCD and their mothers experience many potential difficulties related to the severity of the sickle cell disease, access to medical treatment, family variables, treatment adherence and psychosocial adjustment (Gold et al., 2008). Further, there are some physical and psychological complications related to SCD. These complications negatively interfere with quality of life among individuals with SCD.



Social support is considered one of the important interventions to help individuals with SCD minimize physical and psychological complications related to SCD. Further, parental support has an important role in improving quality of life among individuals with SCD (Sehlo & Kamfar, 2015). Individuals with SCD need to seek successful medical treatment while having social support to ensure the better outcome of minimizing the complications related to SCD (Derlega et al., 2014).

#### Purpose of the Study

The purpose of this study is to understand mothers' perceptions of using Glanz et al. (2002) four social support types in order improve the quality of life of family members with SCD; and the mothers' roles in providing social support to family members with SCD within a family. This study aims to assess the types of social support that mothers provide to their children with SCD. Additionally, this study aims to assess the factors that influence the mothers to provide social support.

#### Research Questions

This research study investigated the following questions:

1. What is the mothers' perception of using social support to reduce physical and psychological complications related to SCD and improve the quality of life?
2. How do mothers use the types of social support to reduce physical/psychological impacts related to SCD and improve the quality of life?

3. What type/s of social support is/are commonly used by mothers of individuals with SCD?
4. What other factors affect the mothers' ability to provide social support?

#### Delimitations

1. Saudi mothers who have children living with SCD.
2. Mothers who have mental or physical disabilities, including elderly mothers will be excluded.
3. The participants will answer the questions related to their knowledge about social support and how they provide it to the members with SCD. Further, they will explain what aspects of social support do they mostly use, and if social support types help to reduce physical and psychological complications related to SCD.
4. The participants will express their challenges they have faced in term of worries they feel about their child's health.
5. The participants will also answer all questions related to their educational level about SCD, and the primary source of information related to SCD, and the severity of SCD.

### Limitations

There are two major limitations to this study. First, there was not a variety of participants in term of educational and occupational level. Most Saudi mothers are housewives, so they have similar life experiences. Second, selecting the time of interviewing was a challenge. It was the Islamic holy month [Ramadan], and celebration after the holy month [Eid Al-Fitr], and people were busy due to fasting, worship, family gathering, and celebration. Choosing the time and a private place for interviewing were challenging. There were three participants who withdrew from the study before the interview due to the time [holy month, and Eid al-Fitr].

### Definition of Terms

Sickle Cell Disease (SCD): Common genetic blood disorder, which it refers to abnormal production of hemoglobin (Hgb) S. Further, when both parents have sickle cell trait, there is a one in four risk with each pregnancy that the children will have the sickle cell anemia (Edwards et al., 2005).

Social Support: resources that meet needs, social relationships through which an individuals' needs are met, or both (Sarason, Levine, Basham, & Sarason, 1983, p 252).

Emotional Support: People who provide support by listening, caring, sympathizing, and making the person feel valued, loved, and respected (Helgeson, 2003).

Instrumental Support: Perceptible assistance and services to help solve practical problems (Helgeson, 2003).

Informational Support: Advice and information that helps the person understand the problem and modify it (Jacobson, 1986).

Appraisal Support: “The provision of information that is useful for self-evaluation purposes, in the other words, constructive feedback, affirmation, and social comparison” (Glanz et al., 2002, p. 186).

## CHAPTER II

### REVIEW OF LITERATURE

The purpose of this chapter is to review the literature related to the importance of social support among individuals who live with SCD. Topics discussed include: (a) physical complications of SCD, (b) psychological complications of SCD, (c) children with SCD, (d) adolescents with SCD, (e) stigma related to SCD, (f) mothers' role of beliefs and attitudes (Saudi culture), (g) the belief in god willing, (h) parental knowledge of SCD, (i) the four types of social support, and (j) why social support is needed.

#### Physical Complications of SCD

Individuals with SCD may suffer from physical complications. Pain associated with SCD is considered one of the widely occurring physical complications of SCD. Pain crisis related to SCD is due to the occlusion of blood vessels by abnormal sickle-shaped red blood cells (Thomas &, Taylor, 2002). It is also one of the complications that most negatively impacts the quality of life among individuals with SCD (Mann-Jiles & Morris, 2009). Pain related to SCD can be either unpredictable or repeated (Gil, Abrams, Phillips, & Keefe, 1989). Since pain related to SCD is a major complication, people with SCD tend to visit emergency to seek emergency care for the pain (Jenerette, Funk, & Murdaugh, 2005). A study conducted by Amr et al. (2011) in both Qatif General Hospital in Qatif, and King Fahad Hospital in Hafouf in Eastern Region, Saudi Arabia, showed that painful episodes were recorded in 56.7 % of cases, individuals with SCD may need to be hospitalized due to severe pain episodes (Burlew, Telfair, Colangelo & Wright,

2000). Demand for emergency hospital admission during the year of 2010 was found in 25.5% of cases.

Another physical complication includes recurrent acute chest syndrome, renal failure, and pulmonary hypertension. Individuals with SCD may suffer from physical complications associated with their disease including delayed growth, fatigue, headaches, and cerebral vascular damage. According to Atoui et al. (2015), bacterial sepsis, sequestration crisis, aplastic crises, ischemic stroke, fatigue, and exercise intolerance are some of the clinical manifestations of SCD. Additionally, 27% of individuals from the Eastern province who have SCD suffer from avascular necrosis of the femoral head. Also, 50% to 80% individuals with SCD in Eastern Province suffer from splenic complications such as sequestration crisis, chronic hypersplenism, splenic infarction and abscess, trauma, and rupture, and 20% required splenectomy (Jastaniah, 2011). The two long-term consequences of SCD, chronic organ damage (Thomas & Taylor, 2002) and stroke, are considered the serious complication related to SCD. Stroke is one of the most common cause of death for individuals with SCD (Mann-Jiles & Morris 2009). Mann-Jiles and Morris (2009) mentioned that individuals with SCD are also at risk to suffer from cognitive impairment which is associated with decreased school performance.

### Psychological Complications of SCD

Because SCD is considered a life threatening disease, individuals with SCD may experience some psychological complications related to this disease. Depression and anxiety have been identified as two major psychological effects of SCD. Frequent hospitalization accounts as one of the major causes of depression among youths with SCD (Jenerette et al., 2005). Additionally, both Derlega et al. (2014) and Barbarin, Whitten, and Bonds (1994) reported that depression related to pain episode is the most frequent sequence occurring among individuals with SCD. Recent studies showed that almost half of the children and adolescents with SCD were diagnosed with either dysthymia 90%; or major depression 10%; (Sehlo, & Kamfar, 2015). Some of them were treated with antidepressant medications (Benton, Ifeagwu, & Smith-Whitley, 2007). Edwards et al. (2005) stated that individuals with SCD often expressed depressive symptoms such as guilt, sadness, helplessness and hopelessness.

Physical appearance could play a role and contribute to the psychological complications related to SCD. Individuals with SCD may experience poor body image due to the physical manifestations of SCD such as jaundiced eyes (Thomas & Taylor 2002). Further, delayed growth and puberty lead to low self-esteem and psychological during adolescents' transition period (Amr et al., 2011; Mann-Jiles & Morris, 2009; Baskin et al., 1998). As a result of feeling low self-esteem, some researchers found that adolescents with SCD experience frequent school absenteeism and low-grade school performance (Mann-Jiles & Morris, 2009).

Interesting to note, uncertainty is another psychological effect of SCD. According to Atkin & Ahmed, “Uncertainty is fundamental aspect of the narrative of young people with chronic disease” (2001, p. 618). Young people with SCD are more prone to worry about their future and how they are going to live with their health condition; possibly affecting mental health.

Thoughts about death are common among adolescents with SCD. They are also at risk to be anxious which can be related to decreased life expectancies (Jenerette et al., 2005). A study conducted by Thomas and Taylor (2002) showed that adolescents with SCD reported that they think about death during the time of painful crisis. They explained that if they do not live normally as other healthy peers and spend most of their time hospitalized, it is not considered a life.

#### Children with SCD

Due to the pain intolerance in children and severity of SCD, pain is considered the main health concern that leads to different complications. For example, pain crisis in children with SCD can result in repeated school absences and reduced physical and social activity (Gil et al., 2001). Seven percent to thirteen percent of all overt strokes occur in children with SCD. Overt stroke causes motor disability and neuropsychological impairment; and in some cases, overt stroke can lead to death (Jastaniah, 2011).

In addition to physical effects that children with SCD may experience, they are at risk to experience psychological effects. Therefore, SCD is also related to increased risk of several developmental outcomes. For instance, children with SCD are more likely to



have behavioral problems at home. A cross-sectional study of 50 children with SCD showed that 64% of children aged seven to twelve experience mother-reported behavior problems (Benton et al., 2007). Additionally, because of severe pain that children with SCD experience, they are at risk to feel depressed, anxious, and face challenges to socialize with other peers (Gil et al., 2001).

Further, children with SCD are at higher risk to experience academic problems because of this disease. A study conducted by Barbarin et al. (1994) showed that there is strong relationship between academic functioning (such as course failure, poor grades, and poor motivation) and SCD. Children with SCD often miss school due to their illness complications. According to Palermo et al. (2002) children with SCD were reported as missing 21% of school days (6-8 weeks per year) because of recurrent pain.

#### Adolescents with SCD

According to Chalise et al. (2007), adolescents with SCD are more likely to exhibit less satisfaction with their body image and experience more symptoms of depression. For example, Thomas and Taylor (2002) have found that individuals with SCD have yellow eyes, which causes them to appear different than individuals who do not have SCD. They are also more likely to experience social withdrawal due to painful crises than healthy adolescents. Furthermore, adolescents with SCD often have difficulty in “individuation”; to be able to be independent through this stage of life. The reason for that feeling is that adolescents are often hospitalized and they receive medical care by a

hospital staff. Receiving hospital services lead to a feeling of helplessness. They also have to rely on parents for health care help (Thomas & Taylor, 2002).

Living with SCD can have a negative impact on forming intimate and social relationship. Adolescents with SCD are less likely to maintain intimate relationships. Further, they often have thoughts about death and dying. This feeling often interferes with and affects their abilities to involve and maintain intimate relationships and get married (Thomas & Taylor, 2007). In some cases, adolescents with SCD feel guilty about the disease. They sometimes ignore the fact that they are ill and want to be as healthy as their peers. Atoui et al. (2015) stated that: “Most of adolescents rejected the idea that their disease created any limitations or encumbered them in any way. For example, Dani, age 17 years, adamantly asserted, “I can do anything I want to!” (p. 429).

#### Stigma Related to SCD

According to Jenerette and Brewer (2010), “health-related stigma refers to a form of devaluation, judgment, or social disqualification of individuals based on a health-related condition” (p. 1). One reason for stigma in a society is the lack of awareness and understanding related to SCD (Burnes, Antle, Williams, & Cook, 2008). Stigma related to SCD has negative impacts that interfere with physical, psychological and social-wellbeing among youths with SCD. Children and adolescents with SCD feel stigmatized and also are at risk to experience the feeling of low competence, low self-esteem and embarrassment due to health related stigma; and that may affect their performance at school (Jenerette, & Brewer, 2010). Negative impacts of stigma could extend to loss of

independent functioning that affects the lives of the individuals with SCD (Hinshaw & Stier, 2008). Additionally, Jenerette et al. (2005) mentioned some of psychological effects related to stigmatization such as self-hate, depression and anxiety. In addition, Barbarin et al. (1994) concluded that children with SCD often experience social isolation due to stigma that is associated with SCD.

Children and adolescents with SCD may be stigmatized by their physical appearance due to physical complications related to SCD. An example of physical appearance is jaundice eyes. A study conducted by Thomas and Taylor (2002) found that one adolescent reporting that they were named a “witch” because of her jaundiced eyes. In addition, stigma related to SCD can take place among certain racial groups. For example, Baskin et al. (1998) pointed out that SCD was called a “black disease” because it is common among African American society. Jenerette et al. (2005) noted that individuals with SCD may be stigmatized because of their physical differences compared to healthy peers. Jenerette and Brewer (2010) also suggested adolescents with SCD are at risk to feel stigmatized by their physical appearance such as late sexual maturation, delayed menarche, and small body mass. The feeling that they utilize a lot at medical services and may result in health-related stigma (Jenerette & Brewer, 2010). Moreover, creating a stereotype has negative impacts on children and adolescents with SCD such as self-hate, depression, anxiety, self-deprivation, and defensiveness (Jenerette et al., 2005).

Since stigma related to SCD is considered a big challenge that interferes in the lives of individuals with SCD, normalization would be a best solution in terms of diminished stigma. Therefore, the goal of normalization is to decrease stigma toward this

disease. Normalization can be one or more of these forms: rejecting the idea that SCD is a chronic illness (seeing it as acute illness instead), comparing children with SCD positively with other healthy peers, and seeing the appearance of children with SCD as a normal appearance (Atkin & Ahmad, 2000).

### Mothers' Roles of Beliefs and Attitudes (Saudi Culture)

Middle Eastern, specifically Saudi culture, is classified as an interdependent culture. Interdependent culture has been identified as one where individuals are encouraged to focus on their relationships and act to maintain harmony within a group (Kim, Sherman, & Taylor, 2008). The study showed that the ability to provide social support tends to be affected by norms and expectation of cultures. Since the Saudi culture is considered an interdependent culture, it is expected that Saudi families are prone to provide social support to their family members. Thus, mothers in an interdependent culture, such as Saudi culture, see social support as an important parenting practice in family life.

Extended family pattern plays a role as a coping mechanism among Saudi community. Amr et al. (2011) illustrated in their study that extended family often hide the anxiety symptoms due to the presence of 'safe persons.' They don't show their worries regarding the health status in order help their member with chronic disease to cope. Amr et al. (2011) also mentioned that the strong relationship between parents and children, family functioning, and active coping/positive attitude regarding SCD are effective coping strategies that are common in Saudi culture.

### Belief in God Willing

Most Muslims, specifically Middle Eastern Muslims, have a high level of belief in God's Will. Many studies have showed that the belief in Muslims' faith is that God is in control of all people's life events. They believe that both illness and cure are from God. Although it is a common belief among the Muslim community, to accept what God gives them, it does not interfere with their efforts to seek medical help (Ezenkwele & Roodsari, 2013). Further, a study conducted by Ismail, Wright, Rhodes, and Small (2005) showed that Muslims have the belief that every life event or challenge comes from God. The strong confidence in belief in the will of God among Muslims helps them feel positive and motivates them to look for the causes of the illness and cure. Therefore, as Atkin and Ahmad (2000) illustrated, some Muslims use their religion as one of their coping strategies. Muslims have the thought that God gives them the illness as well as the strength to cope. Seeking medical care is an essential part of life because it is a common belief that health care professionals are under the influence of God (Inhorn, & Serou, 2011). However, strong belief in God Willing does not mean, in some cases, that a parent will not take an extra effort to take care of their children with SCD in order to improve their quality of life (Atkin & Ahmad, 2000). Additionally, the belief in God Willing could be a good answer to a common question: "Why me?" Atkin and Ahmad (2001) concluded that the question about "Why me?" is frequently asked by adolescents with SCD during the painful crisis and stressful life events. Thomas and Taylor (2002) found that religious beliefs are one of the important factors of comfort for individuals living with SCD.

### Parental Knowledge of SCD

Mothers who have enough information about SCD could provide support for their children and adolescents with SCD. Many studies have shown that there is a connection between health quality of life and parental educational level within families (Amr et al, 2011). Therefore, knowledge of the SCD disease is a key influential factor for providing social support for individuals with SCD. A study conducted by Thomas and Taylor (2002) showed that adolescents with SCD reported that they faced some difficulties dealing with the disease because of the low educational level of their parents related SCD. Atkin and Ahmad (2000) and Logan, Radcliffe and Smith-Whitley (2002) concluded that medical knowledge about SCD helps parents to manage and reduce the severity of SCD. Parents are more likely to use routine doctor visits instead of emergency care (Logan et al., 2002). Moreover, knowledge influences the parents of children with SCD, encourages routine service health care and increases adherence to treatment (Baskin et al., 1998; Logan et al., 2002).

### Types of Social Support

Social support “is the level of resources provided by other persons” (Due, Holstein, Lund, Modvig, & Avlund, 1999, p.663). Social support has four major aspects: emotional, informational, instrumental, and appraisal support. Cohen and Syme (1985) defined informational support as a manner that people provide a needed suggestion, guidance, or information. Informational support can take a part in helping the person to decide to solve problems. Further, information helps people to adopt healthy lifestyle

(Helgeson, 2003) and avoid stressors, especially during stressful-life events (Cohen & Syme, 1985). Emotional support is defined, according to Jacobson (1986) as “behaviors that foster feelings of comfort and lead an individual to believe that he or she is admired, respected, and loved, and that others are available to provide caring and security” (p. 252). Due et al. (1999) pointed out that the confidence between parents and their children is an important part of emotional support. Instrumental support includes parents providing the provision of tangible assistance and services that directly help a person in need. Appraisal support includes parents providing information that is useful for self-evaluation purposes such as, constructive feedback, affirmation and social comparison (Glanz et al., 2002).

#### Why Social Support is Needed

Parents often focused on medical treatments such as blood transfusion and iron chelation and Hydroxycarbamide drug, (Rees et al., 2010), inflammatory, nonsteroidal drug (Chen et., 2004), and oral, intramuscular, or intravenous narcotic (Gil et al.,1989) rather than focusing on the environmental food or environmental support. Also, individuals with SCD may need medical treatments which include antibiotics, adequate nutrition, high fluid intake and folic acid supplement (World Health Organization, 2015). Further, some parents of individuals with SCD also encourage their children and adolescents to adopt healthy (Chen et al., 2004) behaviors such as drinking fluids and avoiding stressors to help them decrease the complications related to this disease. Families also follow the health care service (Logan et al., 2002) to help the members with SCD within a family to cope, decrease physical complications related to SCD and live a better life. However, despite the fact that individuals with SCD need a medical treatment

and adoption of daily healthy behaviors (Chen et al., 2004) many researchers have proven that social support is considered a complementary rehabilitation program that helps to manage health care services.

There is a significant link between social support and improved physical and psychological well-being. For instance, social support has been proven to help individuals with SCD to feel less lonely and experience improve life satisfaction; better-quality psychological wellbeing is considered as an important aspect of quality of life (Mann-Jiles & Morris, 2009; Chalise et al., 2007). Cohen and Syme (1985) illustrated that social support enhances the psychological wellbeing. It helps to promote healthy behaviors and raise self-esteem. Also, Baskin et al. (1998) suggested that lack of family social support is highly linked with psychological distress among adolescents with SCD. In addition, there is a strong relation between mental health, interpersonal satisfaction and physical health (Osman et al., 2014).

Cohen and Syme (1985) mentioned that social support has a major role in treatment and rehabilitation programs. Similarly, Gold et al., (2008) found that social support for individuals with SCD is important for individuals who are challenged to cope with pain episodes and hospitalizations. Moreover, Anie (2005) found that the reduction of the quality of life among individuals with SCD can result from inappropriate pain coping methods. A study conducted by Amr et al., in 2011, concluded that people who suffer from chronic illness such as SCD may report a good quality of life when they receiving social support.



People with SCD need to balance their health conditions with their needs to “normalize their life” (Atkin & Ahmed, 2001). Moreover, supportive and open talks between parents and children with SCD help them to feel less stigmatized by SCD and increase the quality of life, despite that individuals with SCD have challenges that confront living with SCD (Derlega et al., 2014).

Because of some of the psychological complications that individuals with SCD might have (Anie, 2005), social support tends to be an effective measure to cope during stressful life events (Kim et al., 2008). Jacobson (1986) concluded that emotional support tends to be beneficial and the most type of support used during the time of stressor. Therefore, it helps to decrease the feeling of insecurity during stressor time. Brown, Nesse, Vinokur and Smith (2003) indicated that social support is considered a cornerstone in reducing depression and anxiety because of the perception that is related to giving, caring, and belonging. Furthermore, it is interesting to note that the effectiveness of social support for a person who has stressor is equal to a person who does not have any stressor (Cohen & Wills, 1985).

Additionally, several studies show that social support helps members with SCD to become educated about this disorder and become involved to identify and reform the problem as it is a part of SCD treatment (Chen et al., 2004). Chen et al. (2004) mentioned that the complementary nature of medical treatment and social support intervention play a major function to help people with SCD to cope and live a better life.

## CHAPTER III

### METHODOLOGY

#### Research Design

A qualitative design is appropriate to understand mothers' perception of using social support to help their children with SCD live and manage this type of blood disease, as well as to improve their quality of life. Qualitative design is also effective to understand how the families use the types of social support. A semi-structured interview method was used in this study. The purpose of the interview is to let the parents talk about their experience of responsibility of taking care of their children and adolescents who have SCD and explore if the families use social support interventions as a part of effective methods to help the members with SCD within a family to cope in their daily lives.

#### Setting and Research Participants

A convenience, snowball sample of Saudi mothers who have children with SCD and take the primary responsibility to take care of individuals with SCD were recruited to participate in this study. The research study took place in Saudi Arabia, Qatif City in Eastern Province, due to high prevalence of SCD. The respondent criteria were set for mothers ages 18-55 years old. The participating sample of mothers were eventually ages 36-53 years old. Mothers who have physical or mental disability were excluded from participation in this study. The number of interviewed mothers was seven mothers.

### Instrumentation

Interviews were recorded on a password protected recording device. All the interviews were in Arabic language. The transcription process was completed by the researcher transcribing the recordings and notes derived from each interview into a Word document in Arabic language. Transcriptions were then stored on a password secure device as well.

### Procedures for Collecting Data

An interview was conducted with seven Saudi mothers who have children living with SCD. Agreement to participate in the study was obtained prior to the interview process. Oral consent from these mothers was signed prior to completion of the interview process. The interviews were 13-35 minutes in length and were conducted face-to-face in Qatif City in Eastern Province of Saudi Arabia. Participation in this study was completely voluntary. There was no reward for participation.

### The Interview

Interview questions were designed in a semi-structured format that helped engagement between the participant and the interviewer, and helped the participants to be flexible with the experience of providing social support for the children with SCD. A semi-structured interview guide was prepared in both Arabic and English for purposes for IRB, but the interview questions were only used in Arabic. The questions addressed issues related to experience of providing social support to children with SCD. The

interviews were conducted privately at the participant's home or at a coffee shop (five participants at their home, two participants in coffee shop).

### Data Analysis

The transcripts were re-read many times with intention to determine the themes. No prior hypotheses were made to allow the theme to emerge from the data. The main goal was to allow the mothers to express their perceptions and experiences about the given social support to their children with SCD. Names and examples of quotations for each theme were mentioned. Verbatim quotes in the form of descriptive themes are designed in terms to reflect participants' understanding and explanations of their experiences of providing social support to their children who live with SCD. The quotes from the participants reflected the use of social support types according to Glanz et al. (2002). For anonymity, the participants' names have been switched to Participant #1, Participant #2, etc.

### Researcher Bias/Perspective

In Saudi Arabia many people die from SCD. Also, individuals with SCD are suffering from physical and psychological complications related to SCD that interfere with living their lives normally. Additionally, many families in Saudi Arabia, specifically in Eastern Province (Qatif), report that they are not aware that social support may influence individuals with SCD to live better lives. The benefits of social support are not only for individuals with SCD, but also the families and the community will get the benefits as well. Information and knowledge about SCD is the key most powerful factor

of social support (Vaughn et al., 2011). Due to the fact that SCD is a genetic, prevalent, and life-threatening disease, families in Saudi Arabia are in great need of knowledge about their child's/adolescent's illness. Vaughn et al. (2011) suggested that parents usually look for information about SCD by searching in the internet and reading books. Another powerful factor is the relationship between a family and members who are living with SCD. Due et al. (1999) pointed out that social support could be beneficial when the confidence exists in a relationship between parents and their children.

## CHAPTER IV

### RESULTS

A total of seven Saudi mothers of children with SCD were interviewed face-to-face in Qatif city in Saudi Arabia. The interviews took between 13-35 minutes, depending on how mothers expressed their experiences. All the interviews were conducted in Arabic, and the transcriptions were completed (words, phrases) in Arabic. The range of ages of the mothers are between 36 - 53 years old. The ages of children who have SCD are between eleven to seventeen years old. The educational level of the mothers is as follows: three mothers had middle school educations, three mothers had high school degrees, and one has a Master degree.

Most mothers of children with SCD in this study tended to focus and use instrumental and emotional support the most, followed by informational support. No evidence of appraisal support was reported by mothers in this study. There are several factors that affect Saudi Arabian mothers providing social support to their children with SCD, such as a belief in God willing, the role of extended family, and the role of model and beauty concept. Stigma associated with SCD is not common among Saudi community. Additionally, although most of these mothers do not have a college or education, they work hard to educate themselves to be able to help their children to minimize the complications related to SCD and to minimize the doctor visits.

### Instrumental Support

Instrumental support involves the provision of tangible aid and services that directly assist in person in need (Glanz et al., 2002). The main purpose of the use of instrumental support by mothers of children in Saudi Arabia is to decrease physical and psychological complications related to SCD. The mothers frequently reported focusing on healthy diets, mental health (feeling confident and optimistic), and clothing (protecting the children from cold), as well as watching the children for any signs of crisis. Further, interestingly, instrumental support is being used by most mothers in order to reduce hospital visits, in general, and blood transfusions, specifically.

The participants in this study suggested that they have a fear of repeated blood transfusions. They try hard to take care of their child's health to minimize the blood transfusions because of the worry about blood pathogens. Participant # 6, Participant # 4, and Participant # 5 stated that their children with SCD never received blood transfusions due to intensive and protective care at home. Participant # 7 indicated that her daughter had a blood transfusion once when she was seven due to a viral infection, and her Hemoglobin level went to 3 g/dl. She prefers her daughter not have to repeat the experience of the blood transfusion.

Mothers of children with SCD focus a lot on instrumental support, such as providing proper nutrition to their children. The big concern of mothers of providing proper nutrition is the belief that SCD affects the appetite. Participant #6 stated that she struggles with her daughter, eleven years old, who has decreased appetite; and she refuses

to eat healthy meals. Also, mothers tend to depend on beets as a primary, nutritious food for their children with SCD because beets help to raise hemoglobin levels in blood and to avoid anemia. Participant # 6 said:

I always try hard to encourage my daughter, eleven years old, to include beet juice or beet salad and make it as a primary food in her diet. I try to make her carrot and beet juice, or beet salad with lemon. I try to play with taste so that she can accept the taste and like it.

Also, raw garlic, figs, olive oil, orange juice, dates, and raisins are used a lot by the mothers. As Participant # 3 said: "I use garlic a lot in the diet, especially during the crisis. I always use the raw garlic in plain yogurt and salad." Additionally, according to Participant #7: "My husband and I won't let my daughter, thirteen years old, to go to school until she eats the dates, the fig and a cup of milk."

Ultimately, instrumental support could play a part in providing medicines to children with SCD. For example, Hydroxyurea is a medication that is used mostly in individuals with SCD due to its effectiveness in reducing severe pain associated with occlusion of red sickle cells in blood vessels. It is the most common medication that is used by individuals with SCD in Saudi Arabia as well. Participant #4 indicated that Hydroxyurea is very effective in terms of pain relief. She said: "My son, seventeen years old, had an experience of crisis twice a month before taking Hydroxyurea. When he has started to take Hydroxyurea the number of crisis declined." Mothers are anxious about using Hydroxyurea because of the side effects, but they think that they do not have another alternative since it is considered as pain relief medication for severe pain.



Participant #3 said:

My son, seventeen years old, was admitted to the hospital twice a month before he depends on Hydroxyurea. Then, the number of hospital admissions reduced to once monthly because of that medication, because he usually goes to hospital to receive pain relief medication and he already has one at home.

Providing a quiet environment for children with SCD during the painful crisis takes a part in instrumental support. Participant #1 stated that her daughter, fifteen years old, could not hear any noise during the crisis due to severe pain. The mother asked all family members to stay quiet until her daughter could talk and start the daily routine activities again.

Another kind of instrumental support includes helping the child with SCD to take a shower. Participant # 2 reported that she helped her son, fifteen years old, to take a shower during painful crises; because he could not even walk. She also reported that her son felt shame and discomfort when he received help in taking a shower.

Instrumental support does not only include providing proper diet, medication, and clothing, but it extends to watching the child with SCD all the time. If a mother notices any sign of anemia or crisis, she has to take quick action to reduce the complications related to SCD. Participant #3 illustrated that the measurement of the colon is very important because swollen colon is an indication of crisis. She also stated:

The doctor taught us [me and my son seventeen years old] to measure the colon by meter, once I notice any swelling in the colon, I immediately cook food and let him take a rest and calm down. These actions help my son, most times, he feels much better; and sometimes the crisis would go away. When my son ignores the need to measure the colon, he goes through painful crisis. A swollen colon is a big indication of crisis.

Children with SCD are at risk to develop certain types of serious complications such as stroke. So, observing the child to notice any sign of stroke is important.

Participant #3 stated:

Every mother needs to observe any signs of crisis. Mothers should consider the signs of crisis seriously. They should take the children to the hospital immediately because children with SCD are at risk to develop a stroke.

I had an experience with my daughter, seventeen years old. I remember she had a pain crisis, she complained of pain in her chest, and she was admitted to the hospital. She was in the intensive care unit for 24 hours and she had a stroke. The doctor rescued her! Thank God!

Participant #7 suggested that watching her daughter for any SCD is beneficial because painful crises, in most cases, are an indication of any sign of infection or disease.

According to Participant #7:

When I notice any change in my daughter's health, I expect that she has some sort of infection. That's because 95% of sickle cell disease crises are related to infections. I remember one time she had a painful crisis and I got her to the hospital and the doctor told us that she had sore throat infection.

### Emotional Support

Emotional support involves the provision of empathy, love, trust, and caring (Glanz et al., 2002). Mothers of children with SCD tend to be aware of the importance of emotional support. Further, the mothers in Saudi Arabia use emotional support as a primary support to the children with SCD. The reason why emotional support is commonly used by mothers of children with SCD is because of the belief that there is a relationship between the positive/negative feelings and health status of children with SCD. As Participant #1 said: "When my daughter feels down or sad, her health status will get down." Moreover, supportive and open talks between mothers and children with SCD

are important, especially during the painful crises. They also account for one of the major types of emotional support that is used by the mothers. According to participant #6: “emotional support helps my child to stay strong. If we [me and her dad] talk to her during the painful crisis and give her hugs, she can tolerate the pain.” She also added: “During the painful crisis, I asked her this question: ‘Who is stronger you or the disease? This question encourages her to feel I am standing by her.’” Participant # 3 strongly believes that emotional support is a foundation of social support. She said:

Emotional support is really important. If the emotional support is regularly provided by a family, the child will feel optimistic, confident, and strong. The child will be able to take care of her/himself. He/she will be able to socialize with people and perform well in school.

The mothers tend to be aware of the mental and emotional health of people of SCD. Participant #4 explained that people with chronic disease are prone to be sensitive so they need to stay close to the parents and have open communication with each other. Moreover, mothers stated that the children with SCD could not handle the severe pain because their tolerance level is too low because of their children’s age. Participant #5 said:

The pain is bigger than their age. I feel like they are too young to have this pain. So that I try to help them to feel connected with me and loved so that they will have the power to hold the pain.

Also, the mothers suggested that children with SCD need “feeling of attachment” with their families, especially during the time of crisis as it is an essential part of treatment. They have the belief that isolation has a negative impact on their children’s physical and mental health.

Participant #7 indicated:

Helping my daughter with taking a shower, taking medication, and preparing food are important in terms of taking care of her to relieve the pain and improve her health status, but the most important concept is that to you need to help her with 'love.' She needs to feel secure and attached in order to pass this hard time of crisis.

Furthermore, emotional support seems important in case an adolescent has an experience in difficulty in individuation. Adolescents are at high risk to have difficulty in individuation when they receive care by family members due to the chronic illness.

Participant # 2 described her son's feelings, aged fifteen years, when she helped him with his personal care (e.g. taking a shower, feeding him, helping with walking); he feels shamed and sometime angry. She also stated that her son always reminds her that he is a man and he can depend on himself. So, the mother uses emotional support to let him feel comfortable and teaches him that she is his mom and all children should not have negative emotions towards their moms.

#### Informational Support

Informational support is one of the parental support practices for children with SCD. Some mothers of children with SCD in Saudi Arabia rely on informational support as an important type of social support to help their children to be independent and raise awareness regarding sickle cell disease care. For example, participant #5: "I teach my children that taking folic acid pills is very important." Further, the mothers in this study indicated that they face some challenges in teaching their adolescents to take care of themselves to avoid the complications related to SCD. They also indicated that their adolescents do not follow the instructions because of the adolescence age, a time period

in which they develop their personality. So, they, the adolescents, need guidance and affirmation to take care of themselves and to avoid certain medications and foods.

According to Participant #1:

My daughter, fifteen years old, needs someone to remind her to take folic acid. She never takes the folic acid without my warning every day. I have to remind her every day that folic acid is beneficial for her to raise her hemoglobin level.

Participant # 6 also indicated that she always advises her daughter to drink beet juice every day due to its nutritious benefits for individuals with SCD. Additionally, even though most mothers identified themselves as givers of informational support to encourage them, their adolescents, to be independent, several mothers indicated that informational support has greater benefits, so that adolescents with SCD can and will search for accurate information by themselves. Participant #7 explained her that daughter depends on Google Websites to look for accurate information about sickle cell disease.

Participant #7 also said:

My daughter asks about everything related to SCD, I mean the prevention strategies. She knows exactly what to eat and not eat. She always asks me “Mom, Is it okay to eat certain type of food?” She knows how to protect herself in cold weather. She never drinks soft drinks, and she never eats food that contains preservatives. She has knowledge, I would say about SCD. Also, my daughter becomes a role model within a family because she has knowledge about SCD and she knows how to take care of herself!

Since the regular doctor’s visits are important in terms of early detection of any sign of crisis, Participant #3 reported that she always tries to remind her son to have regular checkup appointment. She stated:

I face a challenge with my son, seventeen years old to follow up with him to go to the hospital for regular checkup appointments. He has a car and he drives; and the hospital nearby our home. So no excuse for him! But, even though, he misses some appointments. He seems to be careless and I think because of his age! It is a hard time for adolescents to obey everything we ask for. I need to remind him and follow every time he has to go to the doctor!

On the other hand, mothers reported using less informational support among families who have many members with SCD. They see how other family members suffer from complications and they know the causes of crisis and the prevention procedures to minimize the crisis. Mothers who have cousins and siblings living with SCD suggested that they rarely provide the informational support for their children because the children already have fair knowledge about SCD by watching the members surviving with SCD. According to Participant # 5: “My son, fifteen years old, and my daughter, fourteen years old, have enough knowledge about SCD because they see their aunt and uncle who suffer from SCD.”

Additionally, informational support includes teaching the children and adolescents to avoid risky behaviors. The adolescents tend to adopt risky behaviors such as drinking energy drinks. Participant #5 said:

My daughter, thirteen years old, tried the energy drink once, and she did not like it. I told her it tastes terrible! How could you drink it?! I don't say to my children don't do this, or avoid this, I let them to try what they want so that they will refuse it. I tried not to be constrictive with her so that she can stop drinking the energy drink by herself.

### Role Modeling

Interestingly, using the role modeling also seems effective to one mother of children with sickle cell disease. Modeling is the best method for Participant #4 for delivering informational support to her daughters aged seventeen and fifteen years old.

Participant #4 strongly believes that giving instructions to adolescents with SCD is not effective because they will not follow the directions. She believes that mothers need to find a creative way to allow the adolescents to obey without any challenges. According to Participant # 4: “My daughters will do what I am doing. If I eat healthy, they will eat healthy so I am the role model for them.”

### Beauty

Participant #4 also reported that using the concept of beauty seems effective with her girls with sickle cell disease. The mother used this concept to encourage her daughters, aged seventeen years old and fifteen years old, to eat healthy and to avoid junk food. She said: “I said to my daughters Pepsi makes your skin pale and milk helps to smooth your skin.” She has used this concept since her daughters were young. She raised her daughters to be healthy because health is the door to being beautiful. According to Participant #4: “I told them that you look pale and jaundice because you are anemic. You need to take care of your health so that you will look beautiful.” So that they grow up eating healthy.

### Appraisal Support

In this study, no evidence of appraisal support was reported by mothers in Saudi Arabia.

### School Performance and SCD

Individuals with SCD suffer from physical complications that lead them to missing school or poor performance. Participants in this study reported that most of the school administrators in Saudi Arabia understand the needs of students who have chronic disease. As a result, students with SCD are less likely to perform poorly in school.

Mothers of children with SCD commented that school administrations in general, and teachers specifically, provide aid to their children in many ways. For example, Participant #4 indicated that the teachers repeated the exams for her daughter because she had been admitted to the hospital due to the painful crisis. Similarly, Participant #1 said:

When my daughter, fifteen years old, was in elementary school, she was supposed to have two evaluation tests during the semester. In a case of my daughter had a crisis during the time of second evaluation test, the teachers immediately counted the first evaluation. They knew that she was a good student through the semester, and they tried to help her to feel better rather than make her anxious about the grades.

This school year, she had a crisis during the final exam. She was admitted to the hospital for a week, so that she missed all the final tests. I contacted the school administration and the teachers as well to inform them the hard time that my daughter experienced. They understood the situation. I gave them the medical reports from the doctors and they repeated all the missed final tests.

Participant #5 also reported:

I try to not let my children to miss school. The longest period they did not go to school was five days. Teachers don't have any problem to repeat the tests. I remember last final exams she had a computer practical test. I was worried that the teacher refused to repeat the test since it required the student to attend the lab, but, the teacher was willing to help and she allowed my daughter to take the test.

However, several others reported that their children face some challenges related to school. Some children may experience the crisis during the exams. They are more likely to miss the tests due to difficulty understanding school work which leads them to low performance at schools. Participant #1 said:



During the painful crisis, my daughter gets exhausted due to the severe pain she experiences. I also feel that SCD affects her ability to understand. So that, she misses the school a lot, and I did not know how I can help her with school.

Another challenge is that when a child with SCD needs a surgery during the school time. The surgical procedures for children with SCD often are as a result of physical complications of SCD. For instance, participant #3 stated:

My daughter had a swollen leg due to inflammation, within two hours, the doctor recommended an emergency surgery for her. The school's principal suggested that she find another way of education; it is similar to school home. I refused to go with that solution. Although she missed school for a month due to the surgery, she passed this hard time, and the school understood the situation and respect my decision.

#### Lack of Stigma related to SCD

Stigma related to SCD was not commonly reported by the sample of Saudi mothers. Stigma did not act as a buffer to providing social support. Besides, children with SCD did not suffer from stigma due to four factors. The first factor exists at home. Participants suggested that the child's positive feeling and attitudes stemmed from the family. How family treated the child with SCD affected his/her ability to feel less stigmatized, even if it truly exists in the community. Comments such as: "The family could raise their child with SCD as a normal person and he/she could normalize the life and feels happy and optimistic." "I asked my daughter to help in house chores because I always tell her that you are tired, not 'sick.'" Or "my daughter was affected by the word 'sickle cell disease,' but I helped her to get over this feeling." In another example, Participant #3 indicated that her son is a tennis player. He loves physical activity and his interest is to play tennis. She said:

My son, seventeen years old, suffers from pain associated to SCD, especially backache, but he loves to play tennis. We encourage him to do what he wants because we want him to live as a normal person not a person who has a chronic disease. I think exercising helps him to build relationship with others and improve his mental health.

Although some children with SCD may feel different than healthy peers, the family can help them to normalize the life and live better. According to participant # 3:

My daughter did not accept that she has SCD when she was young, she felt different than other healthy peers. But I have been raised her to accept the truth and she can live a normal and happy life. Now when she grows up she can help me with house chores now and never feels different than others.

The second factor is that the Saudi community seems to recognize the nature of SCD as a genetic disease and no one has control over it. The reason why the Saudi community might have less stigma related to SCD is that the belief in “God willing” plays a major role in feeling less stigma for children with SCD in Saudi culture. Mothers reported that they have high belief in God’s will and they repeated that many times during the interview. All participants in this study reported that have the belief that the diseases come from God and all things from God need to be accepted in order to accommodate the challenges. Additionally, families understand that children with SCD are born with this disease. Comments made by mothers clearly indicated that the perception of stigma related to SCD interferes with the improving the mental/emotional health of child with SCD, as well as parental support to the children.

The third factor that may explain the lack of stigma is the social life in Saudi Arabia. The social life is one of the important aspect of Saudi families. Most families suggested that they encouraged their children to socialize with other peers. Participant #5 explained how her son, 15 years, and her daughter, 14 years old, stay connected with

their friends except during the time of hospitalization. Also, a mother of girls, aged seventeen and fifteen years old, indicated:

I allow my daughter to hang out with their friends to go to malls without parental supervision and enjoy her time with them. I strongly believe that adolescents who disconnect from others may at risk to have low self-esteem and low self-confidence, or they have very conservative, or [close minded] parents and I am not like this. I want my daughters to enjoy the life and to normalize their health condition.

Stigma related to SCD seem to be less among families who have three or more members living with SCD (close and extend families). Those who lived with SCD tend to support others who have the same disease. Besides, facing the physical and psychological complications within families helps the members to see the disease as normal conditions.

Although my daughter recognizes that she has SCD and she has to adjust with her situation forever, but she never feels different, at least within my family, because most of my family members have SCD. the perception of all my family members' related to this kind of blood disease, I would say, is positive. All of them never treat the members with SCD as a challenge or miserable situation.

The last factor is children with SCD who receive decent informational support are less likely to feel stigmatized. For example, Participant #7 stated:

My daughter has high level of knowledge regarding SCD. for example, when we all go to the swimming pool, she knows that she is not able to swim because she is at risk to have crisis due to sudden exposure from cold to heat or from heat to cold. She never feels that she is not normal person or that she is a person who could not enjoy the life.

Participant #7 also added:

Another example, this year we are planning to go to Canada during Christmas break. My daughter cannot travel with us because the cold weather will lead her to fall into a crisis. She totally understands the situation. She never asks why she can't go; she understand it is a risky place for her.

### The Belief in God-Willing

The faith belief in “God Willing” is one of the cultural practices among the Saudi community. There was no question related to belief in “God Willing” in the interview questions. However, all the mothers’ answers showed that the belief in God’s will play a major part in their lives. The belief in God’s will is repeated many times during the interviews. The religious belief is one of the essential comfort factors for parents of children with SCD. Mothers reported that the frequent question asked by children and adolescents who are living with SCD is: “Why me?” Participant #2, Participant #5, and Participant #6 reported that they usually hear this question asked by their children specially during the painful crisis. Participant #6 informed her daughter, eleven years old, that patience and tolerance is the best solution during the painful crisis because that what God’s will to them. Also, they believe that patience during crisis gives them the strength to cope.

The belief in God Willing is considered the best answer of that question “Why Me?” It helps the children with SCD and their parents to stay positive and motivate them to take proper management of the disease. According to Participant #7: “I don’t need to inform my daughter to accept the reality that she has chronic disease like SCD. She knows exactly that the illness is from God and the cure is from God as well.”

Some mothers use spiritual belief as emotional support. Participant # 6, mother of a girl, aged eleven years old, used the belief in God willing as a way to help her child to

stay patient. She has the belief that people with chronic disease such as SCD will be rewarded by God if they are patient to the pain and complications associated to SCD.

Also, according to Participant #7: “My daughter, thirteen years old, accepts the real fact that she has a disease that has no cure. Participant #5, son aged fifteen and daughter aged fourteen, teaches them that everyone has a problem; SCD could be one of the problems in life; and people will be rewarded by God if they accept and not complain about the problem.

During the painful crisis, some mothers tell some sentences from holy Qura’an (رب إني مسني الضر و أنت أرحم الراحمين). The translation of this sentence: “I am afflicted with some distress, and you are the Most Merciful- of all who show mercy.” (Noorduiddin,1997, p. 358). Mothers not only read the holy Qura’an to their children, but also encourage them to read. The belief of reading Qura’an helps the children with SCD to alleviate the pain. “During the painful crisis my daughter could not even talk, but I encourage her to repeat the sentence many times as she could. While she is in pain she could not, but when the pain goes down a little bit she can repeat the sentence.”

#### Socioeconomic Status and Social Support

Three mothers have a middle school, three of them have a high school, and one has a master degree level education. However, all the mothers in this sample were adequately able to supply social support whatever the degree of education they held. The reason of being aware of social support might be that social support is one of the important parental and cultural practices in Saudi Arabia. Besides, mothers with high or

intermediate school degrees are housewives, so they are available all the day at home and they provide care for all children and are focused on children with chronic disease such as SCD. Participant #3, a house wife and intermediate school holder reported: “I try to go to Sickle Cell Disease educational lessons at the health center near my home and at the general hospital too. I try to attend them all and not to miss any one.”

### Knowledge about SCD

Although, as it is mentioned above, most mothers of children with SCD in this study do not have a college education, they provide fair social support to their children. They pursue and utilize accurate information in order to provide adequate social support. Participant #3 reported that she attends the SCD educational lessons that provided by health educators at the health center regularly to assure that she gets the accurate knowledge.

Furthermore, social media sites sever as sources of information related to SCD. Instagram is the most commonly used social media site by mothers to get or read some information. Many doctors, health education specialists, and dietitians have accounts on Instagram. Participant #1 said:

I used Instagram to read what children with SCD need to reduce the numbers of hospital visits, especially the nutrition. I focused on what are the food that elevate the hemoglobin level.

Additionally, participant #1 stated that her sister-in-law has a famous account in Instagram (for advertisements and sharing different experiences) and she helped her to find some information related to proper care of children with SCD. Additionally, mothers

in Saudi Arabia use the What'sApp application to receive broadcasts about sickle cell disease care. Participant #7 indicated that she received broadcast about proper care in general and proper diet, in specific. Participant #7 also stated:

Since we knew when we knew our daughter will live with SCD forever, we try to get enough knowledge about sickle cell disease care by searching online or (googling), and we taught our daughter from the early age so that she knows what to eat what to avoid to eat in order to improve the health status.

Since SCD is a genetic disease, the extended family members may have the same disease. Some families of children with SCD depend on personal and families' experiences as a kind of knowledge. Participant #4 stated: "I know what SCD is because my siblings live with this disease and I have learned a lot from these experiences."

Doctor visits (hematologist) count as the second primary source of information because she is learning the proper care from asking the doctor. Participant #6 mentioned that her uncle is a hematologist at a popular hospital in Eastern Province and he educates her about SCD and proper care of patients; such as taking plenty of fluid daily.

Mothers raised in families that have SCD already have the background knowledge related to SCD. Participant # 5 mentioned that she knows the risky behaviors they can avoid and the healthy behaviors they can adopt, due to the fact that she has SCD and her sibling have the same disease too. Additionally, she teaches her son, fifteen years old, and her daughter fourteen years old, what she already knows. She stated:

Because we live (me and my siblings) with SCD, I try to teach my children to avoid or minimize vigorous activities, avoid stress, and eat healthy in order to minimize the hospital visits and to enjoy their life.

Participants expressed that taking care of their children (personal experience) account as primary sources of knowledge related to SCD. Participant #6 also reported that the primary source of knowledge is personal experience because her daughter, fifteen years old has SCD.

### Challenges Mothers Have Faced

The most common challenge that was reported by mothers was being exhausted, especially during the time of painful crisis. Feeling exhausted results from not getting enough sleep due to worrying about the child's health. Additionally, mothers provide all the child's needs during the night such as medication and food and help the child to sleep when he is not able to sleep due to severe pain. Participant # 6 suggested that the only time she could take a nap during the painful crisis is when her daughter, eleven years old, receives a pain relief shot. According to Participant #3:

I don't get enough sleep during the painful crisis. When my son is admitted to the hospital, I feel worried about my other children at home, and my son who is suffering from the severe pain all day long. I feel like I wish if I can do something to stop the pain! But I can't!

Participant #5 illustrated:

I feel exhausted during the painful crisis; because I have two children with SCD. They both experience painful crises and I need to take care of both of them. I always advise them not to do anything risky, such as drinking soft and energy drinks to stay healthy, to avoid falling into painful crisis. If I get tired, my children will in trouble because they need me!



### Feeling of Guilt

Despite the fact that SCD is a genetic disease, and parents carry this gene, some of mothers reported that they feel guilty because they passed this gene to their children. Furthermore, some of the mothers also reported that they did know that they have the gene, which was the biggest shock for them. Comments by mothers who have sickle trait and their husbands as well, included “My daughter needed a surgery at the age of five, at the time we knew she has SCD through blood tests, my husband was upset and hurt!” or “Although symptoms of sickle cell disease cannot be noticed in babies, the doctor asked for blood tests when my son was born, which made us shocked... why?” or “We [me and my husband] did not think to make premarital blood test, once we knew our daughters have SCD, we would not think to have more children” or “When my daughter was four years old, she had a fever; my nephew is a doctor and he recommended to take blood test, we [me and husband] were shocked when we were informed the result” exemplify this point.

Moreover, the feeling of guilt leads mothers of children with SCD to increase efforts of using social support; with variation of using the types, to minimize the number of hospital admissions due to complications. As Participant #7 said:

We (me and my husband and my oldest daughter and my youngest son) were shocked when the doctor told us that my daughter at the age of four, has SCD. We all repeated the blood test just to make sure, and we all had sickle cell trait and my daughter has SCD.

According to Participant #5:

I thought my husband did not have sickle cell trait until we had our son. I have SCD and I suffer from the complications; and I do not want my kids to have the same experience with this disease.

Further, even though the Saudi community was not aware about blood marriage and inherited blood disease, some mothers with SCD tried hard to plan, before they got married, to marry to men who do not have the Sickle Cell trait. However, some issues were beyond their control especially when both partners got the unclear blood results.

Participant # 7 stated:

Although my father worked at popular hospital in Saudi Arabia, the hospital did not inform us we have sickle cell trait. When we had our daughter and the blood tests showed that she has SCD; we all were shocked. I told my husband that the hospital lied at me. I repeated the blood test three times. It was hard to me to believe that our daughter has SCD, but I don't have any option. All we can do is take care of her.

Participant # 1 said:

I completely ignored what the doctor said when he informed me that my daughter has SCD at the age of two. I was shocked, not because my daughter has this disease, but also the hospital did not inform us the percentage of SCD, it is high and we were informed.

#### Perception/ Effect when a Family Member Died from SCD

As mentioned earlier, thoughts about death are common among adolescents with SCD. Adolescents with SCD expect to decrease life expectancy due to the physical complications related to this disease. Further, the results of cousins within a family dying from this disease affects how the adolescents with SCD deals with SCD. In other word, adolescents with SCD visualize themselves to be the next one who die from SCD.

According to Participant #7: "My daughter, thirteen years old asked me several times this question: 'What if I died like my cousin who had the same disease, what will happen to

you?” Although the mother believed that anyone dies from any reason, not just because of SCD, but she reported that her daughter has the fear of death because of SCD. The mother said: “My daughter keeps silenced and depressed about anyone who died from SCD.”

The belief of dying is a part of belief in God’s willing, but the thought of death from certain types of chronic disease such as SCD causes the fear of lost children to the mothers. Participant #7 illustrated the idea of the effect of someone who died of SCD on individuals living with SCD and for parents as well. Comments such as “I have this thought, What if my daughter dies at any moment?” or “I am not sure if my daughter will be back home after the painful crisis” demonstrate the point of fear of death of SCD. in addition, Participant #7 said:

My niece, who was so close to my daughter, died of SCD as a result of stroke while she was sleeping. It was a big shock for all of us because she just came from the hospital that night after receiving a blood transfusion and pain relief medication. As a result, we all have the thought that our loved ones could die from SCD at any time. My daughter sleeps with us [me and my husband] during the time of crisis or when she feels down. I have this fear of death during sleeping.

#### Extended Families’ Effects to Provision of Social Support

Regardless whether the parents and other family members have SCD or not, living near by the extended families plays a major role in providing social support to children with SCD. In this study, living and getting close with extended families help mothers of children with SCD to stay strong, and made them focus their children’s needs, especially during painful crisis. Participant #1 lives with her family and her sisters-in-law at the same big house. During the painful crisis, her sisters-in-law would help in taking

care of other children and the mother could stay with her daughter who has SCD at the hospital or at home taking care of her without worrying about the other children.

Additionally, living with extended families and blood marriage play a role for social support. For example, Participant #7 explained how they live together (her sisters and her brothers-in-law) and all of them take care of children who live with SCD within the family. She explained how her own children live with their cousins as siblings. Her brothers-in-law treat her children as their children. She also illustrated that the reason they take care of all the children is because every parent (all the parents have sickle cell trait; so some of their children live with SCD and some of their children have sickle cell trait) has the same painful experience with the child with SCD. It is a kind of supportive way to each other, they all help each other to stay strong. Participant #7 gave an example of how the family members live together. As we know, swimming can be risky for children with SCD because of sudden exposure from heat to cold or from cold to heat. When they go to the swimming pool together, her daughter, fifteen years old, goes immediately to her uncle's or auntie's house to spend her time with her cousin who also has SCD without any feeling of guilt or sadness. Since Saudi Arabia is hot (100 F) people go to indoor swimming pools which have air condition; so it can lead to painful crisis.

## Summary of Results

### Instrumental Support and Emotional Support

Participants in this study focused and used the instrumental support and emotional support the most. Due to their belief that the child with SCD does not only need to do things such as eat, sleep well, and take medications, but also that the child needs to feel secured and attached. The participants' beliefs and attitudes towards the use of both instrumental support and emotional support show that the mothers are aware of social support types and how to utilize them to reduce the physical and psychological complications related to SCD.

### Informational Support and Role Modeling /Beauty Concept

Although providing informational support includes providing suggestions and advices for children with SCD, Participant #4 used creative ways to deliver her suggestions and advices (role modeling and beauty concept) to her daughters with SCD to ensure better understanding of the nature of SCD and appropriate management.

### The Belief of God-Willing

As mentioned earlier, the belief in God willing is common belief among Saudi culture. It was expected that mothers have the belief in God willing as a coping strategy. Mothers repeated their beliefs in God willing during the interview although there were no questions related to God willing. Mothers use some sentence from Holy Qura'an and

teach their children these sentences to help themselves to cope especially during the painful crises.

### Stigma Related to SCD

Although literature review showed that stigma related to SCD is common due to the physical appearance and both physical and psychological manifestation of SCD, stigma related to SCD seems to be less common in Saudi community. The participants in this study try hard to help their children to cope and they are aware that feeling stigmatized could interfere their ability cope.

## CHAPTER V

### CONCLUSION AND DISCUSSION

In general, the Saudi Arabian mothers interviewed are aware of the importance of social support to their children with SCD. They believe that social support improves physical and psychological health. Further, instrumental support is commonly used by mothers of children with SCD, followed by emotional support, then lastly, informational support is used. Mothers in the study did not report that they use the appraisal support.

Examples of instrumental support include providing proper food, medication, clothing, and quiet environment, helping the child take a shower and watching the child's health for any signs of crisis or stroke. Emotional support is necessary for the children with SCD in terms of helping the children to stay positive and strong especially during the painful crises. Mothers reported that supportive and open talks help is an important kind of emotional support. Informational support is important in terms of raise awareness related to sickle cell disease care. Informational support takes an account in teaching the child the benefits of taking some medication such as folic acid pills and some types of food such as beets, and reminds the child to take the proper food and medication. It also accounts in reminding the adolescent with SCD about doctor appointments. An interesting finding, the role of beauty and role model, are two major types of informational support used by a mother in Saudi Arabia.

Although educational level plays a role in providing social support to the children with SCD, mothers in this study try hard to gain knowledge related to SCD regardless

their educational level. Attending educational lessons at health centers, following social media sites for doctors and health care specialists, doctors' visits and personal experiences related to living with families who have SCD are the major sources of knowledge related to SCD.

The belief in God's Will plays a major role in providing social support to children with SCD. Although there was no question related to God's will, the mothers in this study repeated their faith about God's Will many times during the interview. The belief in God's will is a good strategy to cope for both mothers and the children with SCD, especially during the painful crisis. The mothers also teach the child some sentences from the holy Qura'an to help the child feel comfortable during the painful crisis. Additionally, the believe in God's will is considered the mothers' roles to provide emotional support as well.

Stigma related to SCD was not common among Saudi community. Stigma related to SCD does not account as a buffer for providing social support due to five factors. The first factor is 'normalization' exists at home. The second factor, the belief in God's will plays a role in behaviors and attitudes among Saudi community. Since SCD is a genetic disease and comes from God, Saudi community believes that no one has control over it. The third factor is social life. Socialized people who have SCD tend to feel less stigmatized due the positive feeling and normality that they gain when they stay connected with other peers. The fourth factor is individuals who live within families who have three or more members living with SCD tend to feel less stigmatized by SCD.



Therefore, they consider SCD as a normal condition. The last factor is children who received decent informational support are less likely to feel stigmatized by SCD.

### Implications for Practice

Qualitative study (such as semi-structured interview mothers in this study) is a good method to gain primary information about the pattern of social support provided to children and adolescents with SCD. This information can be used to modify assessment needs for children and adolescents with SCD. Additionally, the information on the physical and psychological complications related to SCD might help in the planning and implementation in terms of raised awareness regarding using of social support types that are culturally appropriate.

### Recommendations for Future Research

#### Physical Complications

Participants in this study suggested multiple physical complications related to SCD such as erosion of pelvis, pulmonary inflammation and severe back and chest pains. On one hand, the complications depend on the severity of sickle cell disease. Individuals with high percentage of SCD are at higher risk to develop these complications. On the other hand, each physical complication related to SCD might be a result of lack of proper management of SCD. Proper nutrition, mental health and physical activity can help to minimize the physical complication. Future studies could further explore these topics because they are not frequently mentioned in the literature.

### Case Study of a Family Who Has Had a Member Died from SCD

Although the main purpose of this study was to understand how families use social support to help minimize the psychological and physical complications related to SCD, and factors that influence mothers' ability to provide social support for their children; there was a participant who had a niece who died from stroke as a result of complications related to SCD. The death of a family member who died from this disease affects the whole family in the way of their perception of life and death, the relationship the family members together, as well as the management of this disease. Future studies could explore a family like this in greater depth.

## REFERENCES

- Al-Qurashi, M. M., El-Mouzan, M. I., Al-Herbish, A. S., Al-Salloum, A. A., & Al-Omar, A. (2008). The prevalence of sickle cell disease in Saudi children and adolescents. A community-based survey. *Saudi Medical Journal*, 29(10), 1480-1483.
- Amr, M. A. M., Amin, T. T., & Al-Omar, O. A. (2011). Health related quality of life among adolescents with sickle cell disease in Saudi Arabia. *Pan African Medical Journal*, 8(1).
- Anie, K. A. (2005). Psychological complications in sickle cell disease. *British Journal of Haematology*, 129(6), 723-729.
- Atkin, K., & Ahmad, W. I. (2000). Family care-giving and chronic illness: how parents cope with a child with a sickle cell disorder or thalassaemia. *Health & Social Care in The Community*, 8(1), 57-69.
- Atkin, K., & Ahmad, W. I. (2001). Living a 'normal' life: young people coping with thalassaemia major or sickle cell disorder. *Social Science & Medicine*, 53(5), 615-626.
- Atoui, M., Badr, L. K., Brand, T. D., Khoury, R., Shahine, R., & Abboud, M. (2015). The Daily Experiences of Adolescents in Lebanon with Sickle Cell Disease. *Journal of Pediatric Health Care*, 29 (5), 424-433.
- Barbarin, O. A., Whitten, C. F., & Bonds, S. M. (1994). Estimating rates of psychosocial problems in urban and poor children with sickle cell anemia. *Health & Social Work*, 19(2), 112-119.
- Baskin, M. L., Collins, M. H., Brown, F., Griffith, J. R., Samuels, D., Moody, A., ... & Kaslow, N. J. (1998). Psychosocial considerations in sickle cell disease (SCD): The transition from adolescence to young adulthood. *Journal of Clinical Psychology in Medical Settings*, 5(3), 315-341.
- Benton, T. D., Ifeagwu, J. A., & Smith-Whitley, K. (2007). Anxiety and depression in children and adolescents with sickle cell disease. *Current Psychiatry Reports*, 9(2), 114-121.
- Brown, S. L., Nesse, R. M., Vinokur, A. D., & Smith, D. M. (2003). Providing social support may be more beneficial than receiving it results from a prospective study of mortality. *Psychological Science*, 14(4), 320-327.
- Burlew, K., Telfair, J., Colangelo, L., & Wright, E. C. (2000). Factors that influence adolescent adaptation to sickle cell disease. *Journal of Pediatric Psychology*, 25(5), 287-299.

- Burnes, D. P., Antle, B. J., Williams, C. C., & Cook, L. (2008). Mothers raising children with sickle cell disease at the intersection of race, gender, and illness stigma. *Health & Social Work, 33*(3), 211-220.
- Chalise, H. N., Saito, T., Takahashi, M., & Kai, I. (2007). Relationship specialization amongst sources and receivers of social support and its correlations with loneliness and subjective well-being: A cross sectional study of Nepalese older adults. *Archives of Gerontology and Geriatrics, 44*(3), 299-314.
- Chen, E., Cole, S. W., & Kato, P. M. (2004). A review of empirically supported psychosocial interventions for pain and adherence outcomes in sickle cell disease. *Journal of Pediatric Psychology, 29*(3), 197-209.
- Cohen, S., & Syme, S. L. (1985). Issues in the study and application of social support. *Social Support and Health, 3*, 3-22.
- Cohen, S., & Wills, T.A. (1985). Stress, social support, and the buffering hypothesis. *Psychological bulletin, 98*(2), 310.
- Derlega, V. J., Janda, L. H., Miranda, J., Chen, I. A., Goodman, B. M., & Smith, W. (2014). How Patients' Self-Disclosure about Sickle Cell Pain Episodes to Significant Others Relates to Living with Sickle Cell Disease. *Pain Medicine, 15*(9), 1496-1507.
- Due, P., Holstein, B., Lund, R., Modvig, J., & Avlund, K. (1999). Social relations: network, support and relational strain. *Social Science & Medicine, 48*(5), 661-673.
- Edwards, C. L., Scales, M. T., Loughlin, C., Bennett, G. G., Harris-Peterson, S., De Castro, L. M., ... & Killough, A. (2005). A brief review of the pathophysiology, associated pain, and psychosocial issues in sickle cell disease. *International Journal of Behavioral Medicine, 12*(3), 171-179.
- Ezenkwele, U.A., & Roodsari, G.S. (2013). Cultural Competencies in emergency medicines: caring for Muslims-American patients from the Middle East. *The Journal of Emergency Medicine, 45*(2), 168-174.
- Gil, K. M., Abrams, M. R., Phillips, G., & Keefe, F. J. (1989). Sickle cell disease pain: relation of coping strategies to adjustment. *Journal of Consulting and Clinical Psychology, 57*(6), 725.
- Gil, K. M., Anthony, K. K., Carson, J. W., Redding-Lallinger, R., Daeschner, C. W., & Ware, R. E. (2001). Daily coping practice predicts treatment effects in children with sickle cell disease. *Journal of Pediatric Psychology, 26*(3), 163-173.

- Glanz, K., Rimer, B. K. & Lewis, F. M. (Eds.). (2002). *Health Behavior and Health Education Theory Research and Practice*. (3rd ed.) San Francisco, CA: Jossey-Bass.
- Gold, J. I., Treadwell, M., Weissman, L., & Vichinsky, E. (2008). An expanded Transactional Stress and Coping Model for siblings of children with sickle cell disease: family functioning and sibling coping, self-efficacy and perceived social support. *Child: Care, Health and Development*, 34(4), 491-502.
- Helgeson, V. S. (2003). Social support and quality of life. *Quality of Life Research*, 12(1), 25- 31.
- House, J. S., Landis, K. R., & Umberson, D. (1988). Social relationships and health. *Science*, 241(4865), 540-545.
- Hinshaw, S. P., & Stier, A. (2008). Stigma as related to mental disorders. *Annu. Rev. Clin.Psychol.*, 4, 367-393.
- Inhorn, M. C., & Serour, G. I. (2011). Islam, medicine, and Arab-Muslim refugee health in America after 9/11. *The Lancet*, 378(9794), 935-943.
- Ismail, H., Wright, J., Rhodes, P., & Small, N. (2005). Religious belief about causes and treatment of epilepsy. *Br J Gen Pract*, 55(510), 26-31.
- Jacobson, D. E. (1986). Types and timing of social support. *Journal of Health and Social Behavior*, 250-264.
- Jastaniah, W. (2011). Epidemiology of sickle cell disease in Saudi Arabia. *Annals of Saudi Medicine*, 31(3), 289.
- Jenerette, C. M., & Brewer, C. (2010). Health-related stigma in young adults with sickle cell disease. *Journal of the National Medical Association*, 102(11), 1050.
- Jenerette, C., Funk, M., & Murdaugh, C. (2005). Sickle cell disease: A stigmatizing condition that may lead to depression. *Issues in Mental Health Nursing*, 26(10), 1081-1101.
- Kim, H. S., Sherman, D. K., & Taylor, S. E. (2008). Culture and social support. *American Psychologist*, 63(6), 518.
- Logan, D. E., Radcliffe, J., & Smith-Whitley, K. (2002). Parent factors and adolescent sickle cell disease: associations with patterns of health service use. *Journal of Pediatric Psychology*, 27(5), 475-484.

- Mann-Jiles, V., & Morris, D. L. (2009). Quality of life of adult patients with sickle cell disease. *Journal of the American Academy of Nurse Practitioners*, 21(6), 340-349.
- McClish, D. K., Penberthy, L. T., Bovbjerg, V. E., Roberts, J. D., Aisiku, I. P., Levenson, J. L., ... & Smith, W. R. (2005). Health related quality of life in sickle cell patients: the PiSCES project. *Health and Quality of Life Outcomes*, 3(1), 1.
- Noorduiddin, A., (1997). *The Holy Qur'ân: Arabic Text- English Translation*. (2<sup>nd</sup> edition). Hockessin, DE: Noor Foundation-International Inc.
- Osman, A., Lamis, D. A., Freedenthal, S., Gutierrez, P. M., & McNaughton-Cassill, M. (2014). The multidimensional scale of perceived social support: Analyses of internal reliability, measurement invariance, and correlates across gender. *Journal of Personality Assessment*, 96(1), 103-112.
- Palermo, T. M., Schwartz, L., Drotar, D., & McGowan, K. (2002). Parental report of health- related quality of life in children with sickle cell disease. *Journal of Behavioral Medicine*, 25(3), 269-283.
- Rees, D. C., Williams, T. N., & Gladwin, M. T. (2010). Sickle-cell disease. *The Lancet*, 376(9757), 2018-2031.
- Sarason, I. G., Levine, H. M., Basham, R. B., & Sarason, B. R. (1983). Assessing social support: the social support questionnaire. *Journal of Personality and Social Psychology*, 44(1), 127.
- Sehlo, M. G., & Kamfar, H. Z. (2015). Depression and quality of life in children with sickle cell disease: the effect of social support. *BMC Psychiatry*, 15(1), 78.
- Thomas, V. J., & Taylor, L. M. (2002). The psychosocial experience of people with sickle cell disease and its impact on quality of life: Qualitative findings from focus groups. *British Journal of Health Psychology*, 7, 345.
- Vaughn, L. M., McLinden, D., Jacquez, F., Crosby, L., Slater, S., & Mitchell, M. (2011). Understanding the social networks of parents of children with sickle cell disease. *Journal of Health Care for the Poor and Underserved*, 22(3), 1014-1029.
- World Health Organization (WHO), (2015). Sickle cell disease prevention and control. Retrieved from: <http://www.afro.who.int/pt/sickle-cell-disease-prevention-and-control.html>

## APPENDIX A

## SOCIAL SUPPORT INTERVIEW GUIDE (ENGLISH)

PARENTAL REPORT OF PROVISION OF SOCIAL SUPPORT TO THEIR  
CHILDREN WITH SCD

Need to limit to oldest child having SCD, so previous experience doesn't influence them.

1- How many children do you have? How many of your children have SCD?

As I ask you questions, I'd like you reflect on your oldest child with SCD experience with SCD.

2- As parents, do either of you have SCD? Both - Mother - Father

3- What are the primary sources of information related to SCD that you use?

- Internet
- Google?
- Social media?
- Books
- Family talk
- Doctor office
- Personal experience
- Other

4- What are a few words you would use to describe how you feel about your child's SCD?

5- What are some of the biggest challenges you have experienced?

6- Can you describe the severity of SCD?

Probe: How often do you bring your child to the hospital?

7- Now let's talk about the challenges your child has experienced:

What challenges with physical health has your child experienced?
What challenges with mental health has your child experienced?
What challenges with school performance has your child experienced?
What challenges with social life has your child experienced?
What challenges with finding information has your child experienced?

8- Probe for each type of support:

(Informational) What do you do to provide info about SC to your child?

(Emotional) What do you do to help your child feel confident or capable to deal with his/her SCD?

(Tangible) What do you do to help your child perform well in school when has problems with SC? Medicine? Vitamins? Blood transfusion?

What do you do to ensure that your child with SC feels connected and loved? Stigma? Feeling different or ostracized?

9- What are usually you doing during the time of pain crisis? (Look for evidence of emotional support, informational support, or instrumental support, belonging support)?

10- What is your age?

➤ 18-24, 25-34, 35 and older refused to answer

11- What degree do you hold?



- high school
- some college
- college graduate
- education beyond bachelor's degree

12- Do you work outside the home?

No, end of interview, thanks

Yes, what is your occupation? Thanks

APPENDIX B  
SOCIAL SUPPORT INTERVIEW GUIDE (ARABIC)

النسخة العربية من أسئلة المقابلة

- (1) هل بإمكانك أن تحدثني عن تجربتك مع أكبر أطفالك المصابين بالسكسل؟
- (2) هل أحد الوالدين أو كلاهما مصاب بالسكسل؟
- (3) ما مصدر الثقافة الرئيس المتعلقة بمرض السكسل؟
  - (a) الشبكة العنكبوتية
  - (i) محرك البحث (قوقل).
  - (ii) وسائل التواصل الاجتماعي.
  - (b) كتب
  - (c) حديث عائلة
  - (d) الطبيب
  - (e) تجارب شخصية
  - (f) أخرى
- (4) هل بإمكانك أن تصفي بكلمات قليلة شعورك تجاه صحة طفلك؟
- (5) هل بإمكانك أن تصفي مدى شدة مرض السكسل التي يعاني منها طفلك؟
- (6) كم مرة تنوم طفلك في المستشفى؟
- (7) هل بإمكانك أن تحدثني عن تجربتك عن العقبات التي تواجهينها؟
  - (a) العقبات المتعلقة بصحة الطفل الجسدية.
  - (b) العقبات المتعلقة بصحة الطفل النفسية.
  - (c) -العقبات المتعلقة بصحة الطفل الاجتماعية.
  - (d) العقبات المتعلقة بمدى معرفة وإدراك طفلك بمرض السكسل.
- (8) أنواع الدعم السري
  - (a) كيف تساعدن طفلك على الحصول المعلومات المتعلقة بمرض السكسل؟ (الدعم المعلوماتي).
  - (b) كيف تساعدن طفلك ليشعر بالامان و الاطمئنان و بأنه قادر على التعايش مع هذا المرض؟ (الدعم العاطفي).
  - (c) كيف تساعدن طفلك ليطور من أدائه الدراسي؟ كيف تساعدن طفلك ليحصل على الأدوية؟ الفيتامينات؟
  - (d) كيف تساعدن طفلك ليشعر بقبول الآخرين؟ أو تقليل من شعوره بالانعزال او الاختلاف؟
- (9) في اعتقادك أي نوع من أنواع الدعم الأسري مهم خلال نوبة السكسل؟
- (10) كم عمرك؟
  - (i) 18-24
  - (ii) 25-34
  - (iii) 35-44
  - (iv) لا أرغب بالإجاب

(11) ماهي درجتك العلمية؟

(a) ثانوية عامة

(b) دبلوم

(c) بكالوريوس

(d) دراسات عليا

(12) هل أنت موظفة؟

(13) هل تعرفين أشخاص مصابين بالسكسل و يرغبون بالمشاركة؟

## APPENDIX C

## INFORMED CONSENT

**UNIVERSITY OF NORTHERN IOWA  
HUMAN PARTICIPANT REVIEW  
INFORMED CONSENT**

Project Title: Saudi Arabia Mothers of Children with Sickle Cell Diseases (SCD) as Givers of Social Support

Name of Investigator(s): Fatimah Alrubh, graduate student

**Invitation to Participate:** You are invited to participate in a thesis project conducted through the University of Northern Iowa. The university requires that you give your verbal agreement to participate in this project. The following information is provided to help you make an informed decision about whether or not to participate. Participation in this project is completely voluntary.

**Nature and Purpose:** The purpose of this study is understand the mothers' perception of using social support to children with SCD as well as asses the types of social support that the mothers use to help their children with SCD. Lastly, this study assesses the factors that influence the mothers to provide social support.

**Explanation of Procedures:** In an interview, you will be asked a series of questions related to social support. Responses will be audio recorded to ensure responses are documented accurately. The responses will be transcribed into word document. Some questions will arise from the conversation between the interviewer and yourself.

**Discomfort and Risks:** Risks to participation are minimal. You may find risk or discomforts from participating in this study related to sharing personal stories or sad life events from past.

**Benefits and Compensation:** There will be no cost or monetary benefit to you if you participate in this study.

**Confidentiality:** Your identify will be kept anonymous whether you agree to or decline from participation. To minimize and potential risks, all responses obtained during the interview will be kept anonymous.

**Right to Refuse or Withdraw:** Your participation in this study is completely voluntary. Refusal to participate or withdrawal from participation in the study will not result in any penalty or loss of benefits or rights to which you might otherwise be entitled.

**Questions:** If you have any questions regarding the nature of this study or desire information in the future regarding your participation or the study in general, you may contact the office of the IRB Administrator, University of Northern Iowa, at 319-273-6148, for answers to questions about the rights of research participants and the participants review process.

May we proceed with the interview? (An answer of yes will be considered consent.)