

**A QUALITATIVE ANALYSIS OF SELF-CARE MANAGEMENT RESOURCES
AMONG CAREGIVERS OF CHILDREN WITH SICKLE CELL DISEASE FOR THE
DEVELOPMENT OF PARENT ADVOCACY TOOLKITS**

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Sickle Cell Disease (SCD) is an inherited blood disorder that affects 80,000 individuals in the United States. SCD is of public health significance as individuals with this disease are at risk of early mortality, morbidity, and disability. These conditions arise as a result of inadequate clinical treatment and improper self-care management, which are potentially modifiable with optimum disease management. The Theory of Self-Care Management for Sickle Cell Disease proposes that self-care management resources have the ability to improve poor health outcomes; however, previous studies indicate that individuals with SCD and their caregivers lack appropriate resources. Consequently, this study was designed to qualitatively assess where caregivers receive self-care management resources; determine what type(s) of information has already been acquired; learn about the type(s) of self-care management resources that intended audiences need; and explore the most appropriate media and channels to disseminate self-care management resources. A focus group was conducted with ten caregivers of children with SCD to facilitate a discussion to address these specific questions. Transcripts were analyzed using the questions from the moderator's guide to generate a table to identify themes that emerged throughout the discussion. Results revealed that caregivers primarily relied on routine services to provide self-care management resources and sickle cell educational information was found to be the only self-care management resource provided. This resource provided "basic"

information, causing caregivers to seek additional information from alternative sources like the internet and by asking questions. Caregivers did not acknowledge receiving additional resources, nor did they report receiving self-care management resources for their children. Caregivers acknowledged the importance of these resources and suggested that they be disseminated through all available media by obstetrician/gynecologist's offices and schools to caregivers based on their individual preferences for receiving the resources all at once or in stages. Furthermore, the caregivers began acknowledging that it may be their responsibility to provide information and education to their communities. Consequently, additional self-care management resources should be created by other caregivers and peers based on their experiences. Further research should be conducted to develop and pretest these self-care management resources and to determine their impact on health outcomes.

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PREFACE

The Children's Sickle Cell Foundation, Inc. has found that following diagnosis, caregivers are given a crash course on sickle cell disease. As a result, many parents are overwhelmed by this information, unsure how to use or interpret the information, and eventually seek additional information during routine visits about how to care for their child. Despite their best intentions, caregivers ultimately lack the necessary knowledge and resources to provide the best possible care for their child. In order to address this issue, the Children's Sickle Cell Foundation, Inc. is planning to Develop Parent Advocacy Toolkits that contain additional information, resources, and tools for parents to better understand and manage their child's disease

This research is dedicated to the children with sickle cell disease and their families, who have opened their lives and shared their stories. A special thank you is extended to Ms. Andrea Williams who recognized the need for this research, entrusted me with her vision, and provided me with the resources to investigate these needs. Also, I want like to thank "Mr. Mike" for his encouragement, support, and hard work that helped to make this project a success. Thank you both for the opportunity to learn and grow while making a difference in the lives of our families.

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within this paper for increasing my knowledge about sickle cell disease and for their important contributions to sickle cell research, which is limited, and for helping to shape this project.

Finally, Dad, Mom, Henna, Hee-Hay, and Wig, thank you all for your unconditional love, support, and encouragement over the past few years. To the boy who got into my head with all the pretty things he did, thank you for all of the tough love and for being there for me when you didn't have to be. It is because of all of you that I am where I am today and for that I am forever grateful.

1.0 INTRODUCTION

Sickle Cell Disease (SCD) is an umbrella term that encompasses a series of inherited blood disorders. SCD is the most common disorder among those of African-American descent and it is estimated that SCD affects 80,000 individuals in the United States and that 1 in every 400-500 babies born in the United States is diagnosed with SCD (Kaslow & Brown, 1995). Individuals with SCD inherit two recessive genes from their parents, which results in the substitution of normal hemoglobin with abnormal sickle hemoglobin during embryonic development. Consequently, these red blood cells do not produce normal hemoglobin and tend to exhibit a sickle (crescent) shape, which are hard, sticky, and inflexible, as opposed to their normal round, smooth, and flexible characteristics. Due to these abnormalities, the red blood cells of individuals with SCD have a shorter life-span than normal red blood cells and do not readily flow through the blood vessels, which can result in what is known as a “sickle cell crisis” (Gustafson et al., 2007; Bennett, 2005; Logan, Radcliffe, & Smith-Whitley, 2002; Treadwell, McClough, & Vichinsky, 2006; Kaslow & Brown, 1995).

There are various types of sickle cell crises. Vaso-occlusions are the most common and occur when sickle cells obstruct blood flow; other crises manifest themselves as a result of increased risk of infection, chronic anemia, stroke, and dehydration (Rees et al., 2003; Bennett, 2005; Logan, Radcliffe, & Smith-Whitley, 2002). Sickle cell crises are characterized by chronic pain which is a major public health problem that hinders the overall goal of Healthy People 2010

(Farrell, Wicks, & Martin, 2004), as it impairs the health and well-being of individuals with SCD with its significant physical, psychological, and socioeconomic implications (Logan, Radcliffe, & Smith-Whitley, 2002; Treadwell, McClough, & Vichinsky, 2006; Kaslow & Brown, 1995)

Studies have indicated that approximately 50% of patients with SCD do not survive into their 40s (McClain & Kain, 2007), as a result of inadequate clinical treatment and improper self-care management of sickle cell crises. Failure to properly treat and manage sickle cell crises can lead to psychological problems including depression, anxiety, attention deficit/hyperactivity disorder, adjustment and interpersonal difficulties, maladaptive cognitions, withdrawal, aggression, poor relationships, low self-esteem, poor academic performance, and neurocognitive impairments (Anie, 2008; Kaslow & Brown, 1995). Morbidity, mortality, and disability associated with SCD are potentially modifiable with optimum disease management (McClain & Kain, 2007). The Theory of Self-Care Management for Sickle Cell Disease proposes that self-care management resources have the ability to improve health outcomes of individuals with SCD (Jenerette & Murdaugh, 2008); however, individuals with SCD and their caregivers have been found to lack appropriate self-care management resources which exacerbates poor health outcomes among individuals with SCD and their caregivers (Anie, 2008; Koontz et al., 2004).

The Children's Sickle Cell Foundation, Inc. (CSCF) is a community-based organization that has also recognized the need for self-care management resources throughout their endeavors of providing educational, economic, and social support to children with SCD and their families. Previous studies have recommended providing age-appropriate, self-care management resources to children with SCD and their caregivers as a way of empowering the parents to advocate for the best possible care for their child (Sterling, Peterson, & Weekes, 1997; Koontz et al., 2004). Based on these recommendations, CSCF is planning to develop Parent Advocacy Toolkits

utilizing health communications strategies to develop and implement self-care management resources.

In order to identify the resources to include in the toolkits, a focus group will be conducted with caregivers of children with SCD to generate a discussion about self-care management resources. The aims of the focus group are to determine: (1) where caregivers are receiving self-care management resources; (2) what types(s) of self-care management resources caregivers received; (3) what type(s) of self-care management resources caregivers and children with sickle cell disease still need in order to improve their quality of life; and (4) how and when self-care management resources should be provided to caregivers and who should provide this information. The results of this discussion will be used to develop the Parent Advocacy Toolkits based on the needs identified by the caregivers, in order to improve quality of life and reduce mortality, morbidity, and disability among individuals with SCD.

2.0 BACKGROUND & PUBLIC HEALTH SIGNIFICANCE

2.1 SICKLE CELL DISEASE

Sickle Cell Disease (SCD) is a generic term used to describe a set of blood disorders characterized by the production of abnormal (sickle) hemoglobin that primarily affect those of African-American descent (specifically from sub-Saharan Africa) (Logan, Radcliffe, & Smith-Whitley, 2002; Houser et al., 1992; Creary, Williamson, & Kulkarni, 2007; McClish et al., 2006; Gil et al., 1989; Mitchell et al., 2007; Ellison & Shaw, 2007). Although SCD is commonly found in African-Americans, SCD has been identified in individuals from other geographical areas where malaria is endemic: Spanish-speaking regions in the Western Hemisphere (South America, Cuba, and Central America), Mediterranean countries (Turkey, Greece, and Italy), East India, Saudi Arabia, the Middle East, as well as the Caribbean (Treadwell, McClough, & Vichinsky, 2006; Kaslow & Brown, 1995; Houser et al., 1992; Creary, Williamson, & Kulkarni, 2007; Mitchell et al., 2007; Ellison & Shaw, 2007; de Montalembert, 2008). SCD is the most common genetic disorder among African-Americans in the United States. It is estimated that sickle cell disease affects 80,000 individuals; 350,000 babies born in the United States are diagnosed with sickle cell disease; and three million individuals have sickle cell trait (Thomas & Cohn, 2006; Treadwell, McClough, & Vichinsky, 2006; Kaslow & Brown, 1995; Houser et al., 1992; de Montalembert, 2008).

2.1.1 Molecular Structure & Pathophysiology of Sickle Cell Disease

Normal red blood cells contain normal hemoglobin (Hb AA), or adult hemoglobin, a protein that enables red blood cells to efficiently transport oxygen throughout the body and does not cause any health problems (Bennett, 2006; Yoon & Black, 2006; Higgs & Wood, 2008; de Montalembert, 2008; Hoffman, 2005). The HBB gene is a series of amino acids responsible for producing normal hemoglobin, consisting of two alpha and two beta chains (Hoffman, 2005). Individuals with SCD have a mutation of this gene caused by the substitution of the amino acid valine for the amino acid glutamic acid at a particular point in the gene, which results in the production of sickle hemoglobin (Hb S) instead of normal hemoglobin. This mutation alters the beta-globin chain during embryonic development which yields compromised hemoglobin production as this mutation alters the structure of this protein and inhibits the red blood cells ability to successfully perform their function (Yoon & Black, 2006; Higgs & Wood, 1992; de Montalembert, 2008; Hoffman, 2005).

SCD is a genetic blood disorder passed on from parents to their children that (McClish et al., 2006; Yoon & Black, 2006; Fuggle et al., 1996; de Montalembert, 2008) occurs when an individual inherits two sickle hemoglobin mutations or one sickle hemoglobin mutation and another hemoglobin variant (the substitution of valine for a different amino acid other than glutamic acid) (Bennett, 2005; Yoon & Black, 2006; Higgs & Wood, 2008; Hoffman, 2005). More than 700 hemoglobin variants exist; however, not all of these variants are clinically significant, as some forms are asymptomatic (Bennett, 2005; Creary, Williamson, & Kulkarni, 2007; Fuggle et al., 1996). The most prevalent forms of SCD are Hb-SS, the most severe form of the disease; Hb-SC, a milder form of the disease; and Hb- β -thalassemia, a moderate form of the disease that resembles Hb-SS in those of Mediterranean and Asian descent (Bennett, 2005;

Creary, Williamson, & Kulkarni, 2007; Ellison & Shaw, 2007). The HB-SS form of the disease accounts for 60-70% of all cases of SCD (Hoffman, 2005); therefore the remainder of this paper will refer to the Hb-SS form of SCD.

Red blood cells of individuals with sickle hemoglobin are round and resemble the red blood cells of individuals with normal hemoglobin when there is an adequate oxygen supply. However, in the absence of oxygen the sickle hemoglobin begins to polymerize (unravel), forming rope-like fiber, which causes the red blood cells to become deformed as a result of the amino acid substitution in the beta-hemoglobin chain. During this process, the cells become dehydrated and the polymer fibers become sticky and attach to one another, which causes the red blood cell to exhibit a sickle (crescent) shape. Consequently, these sickle cells are capable of becoming tangled together and adhering to other cells, including endothelial cells (the inside lining of the blood vessels) (Bennett, 2005; Houser et al., 1992; Higgs & Wood, 2008; de Montalembert, 2008; Hoffman, 2005). The irregular shape of these red blood cells and adhesion to the endothelium trigger an immune response that yields increased polymerization (more sickle cells) and inflammation as the body attempts to destroy the sickle cells. The inflammatory response decreases blood flow and releases granulocytes, platelets, and reticulocytes (Ellison & Shaw, 2007) that interact with and provide additional sickle cells the opportunity to adhere to the other sickle cells attached to the endothelium, ultimately, blocking circulation and oxygen delivery to organs and tissues (infarction) throughout the body (Gustafson et al., 2007; Bennett, 2005; Logan, Radcliffe, & Smith-Whitley, 2002; Treadwell, McClough, & Vichinsky, 2006; Kaslow & Brown, 1995; Higgs & Wood, 2008; Part I Handbook). Organs with slow blood flow (spleen and liver) as well as organs and tissues that require an adequate oxygen supply (brain and muscles) are more susceptible to the effects of sickle cells (Bennett, 2005). Restricted

circulation and oxygen delivery within the body areas can yield serious medical complications that lead to significant morbidity and mortality (Houser et al., 1992; Creary, Williamson, & Kulkarni, 2007).

2.1.2 Sickle Cell Crises & Other Complications

Sickle cell crisis is a general term used to characterize the events that occur as a result of the body's response to the abnormal shape of the red blood cells in individuals with SCD. Some sickle cell crises can be life-threatening and others can cause further complications if not treated properly.

2.1.2.1 Vaso-Occlusion Crisis

Vaso-occlusions are ischemic (restriction of blood flow) events that occur when sickle cells obstruct the flow of blood in individuals with SCD (Rees et al., 2003; Bennett, 2005; Logan, Radcliffe, & Smith-Whitley, 2002; Houser et al., 1992; Creary, Williamson, & Kulkarni, 2007; Higgs & Wood, 2008). Vaso-occlusions can last minutes, days, or weeks; however, studies show that vaso-occlusions typically average five to ten days and vary in intensity ranging from asymptomatic to requiring hospitalization (Bennett, 2005; Houser et al., 1992; Creary, Williamson, & Kulkarni, 2007): 30% of individuals with SCD rarely or never experience vaso-occlusions, 50% have multiple, mild episodes, while the remaining 20% experience frequent and severe vaso-occlusion episodes (Houser et al., 1992). Oftentimes, the pain associated with SCD requires hospitalization as many clinical problems arise as a result of vaso-occlusions and other complications associated with sickle cell disease; vaso-occlusions are responsible for 79-91% of

emergency room visits and 59-68% of hospitalizations (average of five to seven days) (Jacob & Mueller, 2008).

Vaso-occlusions are the most common clinical problem associated with SCD and typically present during early infancy, as early as two to three months (Houser et al., 1992), and generally persist throughout the lifespan (Houser et al., 1992; Creary, Williamson, & Kulkarni, 2007). Vaso-occlusions are typically initiated by one or more of the following: dehydration, physical overexertion, exposure to cold, infection, fever, trauma, infection, stress, fatigue, acidosis (increased acidity of the blood), smoking, alcohol, and/or environments where an adequate oxygen supply is limited (Bennett, 2005; Houser et al., 1992; Creary Williamson, & Kulkarni, 2007; Gil et al., 2003; de Montalembert, 2008). During a vaso-occlusion, infants are typically irritable and 30% of the time exhibit dactylitis, painful swelling of the hands and/or feet, during the first two to three years (Bennett, 2005; Houser et al., 1992; de Montelembert, 2008). In children three years and older, vaso-occlusions commonly occur throughout the musculoskeletal system, typically in the bone marrow of long bones, ribs, sternum, spine, and pelvis due to small capillary beds within these areas. Symptoms typically mimic arthritis, osteomyelitis or rheumatic fever, making it difficult to identify. During adolescence, the most common site of vaso-occlusions is the abdomen (Bennett, 2005; Houser et al., 1992).

2.1.2.2 Life-Threatening Sickle Cell Crises

The abnormal shape of red blood cells in individuals with SCD have a shorter life span (five to ten days) than normal red blood cells (120 days) and are susceptible to destruction by the body's immune system, as they are recognized as foreign cells. As a result, individuals with SCD have susceptible immune systems and often suffer from anemic conditions. Anemia occurs as a result of decreased hemoglobin levels and red blood cell counts that reduce the amount of

oxygen being transported throughout the body, causing tissue damage that can be life-threatening.

The reduction of red blood cell production can be caused by a folic acid deficiency, which results in a megaloblastic crisis. The body needs folic acid in order to produce new cells, thus folic acid is especially important for individuals with SCD, who are constantly producing and replacing red blood cells as a result of their shorter life-span and the immune system's response. If the body is unable to replace red blood cells in the body, individuals are at risk of severe anemia that can be life-threatening. Furthermore, haemolytic crisis occurs as a result of the body's inability to rapidly replace red blood cells, resulting in severe anemia and less oxygen being circulated throughout the body. Oxygen deprivation leads to tissue damage within the body and this type of crisis is known to cause kidney damage, which puts individuals at risk of kidney failure

Additionally, an aplastic crisis yields severe anemia that can result in damage to vital organs, putting individuals with SCD at risk for organ failure. Aplastic crises are caused by the reduction or cessation of bone marrow activity. Bone marrow is located within the hollow center of the bones and is responsible for producing new red blood cells. During an aplastic crisis, red blood cell production is reduced or halted for up to ten days as a result of an infection caused by Parvovirus B19. Infections are common among individuals with SCD as a consequence of splenic sequestration or pooling of large volumes of blood. During splenic sequestration, the sickle cells block the blood flow coming out of the spleen, causing blood to accumulate, resulting in damage to the spleen as it becomes enlarged. As a result, germs and bacteria may not be filtered from the blood stream (the function of the spleen), putting individuals with SCD at

risk of septicemia (infection of the blood), which can be life-threatening (Earles, Lessing, & Vichinsky, 1993).

Recent studies have reported that infection, acute chest syndrome, stroke, and multi-organ failure associated with these forms of crises are the leading causes of death within this population. As a result, approximately 11% of individuals with SCD do not survive to adulthood (Fuggle et al., 1996) and only 50% of patients with SCD survive into their 40s (McClain & Kain, 2007; McClish et al., 2006; Gil et al., 1996).

2.1.2.3 Secondary Complications of Crises

Many complications occur secondary to the ischemic organ damage that occurs during vaso-occlusions. These complications include chronic pain, increased risk of infection, chronic anemia, stroke, dehydration, bone infections, jaundice, acute chest syndrome, priapism (prolonged painful erection), necrosis, ulcers on the extremities, pneumonia, and progressive organ damage to the spleen, liver, and kidneys. Damage to these organs generally results in other long-term conditions such as delayed growth, puberty and sexual maturation (Bennett, 2005; Houser et al., 1992; Creary, Williamson, & Kulkarni, 2007; Gil et al., 1996; Fuggle et al., 1996) as well as an increased risk for early mortality (Logan, Radcliffe, and Smith-Whitley, 2002; Treadwell, McClough, and Vichinsky, 2006; Kaslow & Brown, 1995; McClish et al., 2006; Fuggle, 1996).

2.1.2.4 Chronic Pain in Individuals with Sickle Cell Disease

The sickle shape of the red blood cells in individuals with SCD causes many complications that trigger an inflammatory response from the body's immune system. The inflammatory response is a complex biological response initiated by the body's immune system

to protect against harmful pathogens as well as repairing and healing damaged tissues. During the response, potassium, bradykinin, prostaglandin, and substance P are released into the blood stream and activate or sensitize nociceptors, sensory nerve endings that receive information about painful stimuli and transmit pain signals to the brain. The pain is either acute, lasting several days or weeks, or chronic, pain lasting longer than three to six months (Geller & O'Connor, 2008).

SCD is characterized by acute episodes of pain. According to Geller and O'Conner (2008), sickle cell crises have four distinct phases that constitute its pain cycle: (1) Prodrome Phase: symptoms of numbness, aches, and paralysis appear in areas affected by pain and lasting up to two days; (2) Initial Infarct Phase: pain that increases gradually after the Prodrome Phase; (3) Post-Infarct Phase: persistent and severe pain accompanied by inflammation; and (4) Resolution Phase: gradual remission of pain after treatment has been administered. Inadequate treatment during the Resolution Phase causes damaged tissues to enhance sensitization of nociceptors to indicate that the pain has not been fully resolved, causing them to become desensitized, which leads to the development of chronic pain conditions. Several studies conducted by Basbaum and colleagues have reported that chronic pain in individuals with SCD is not prolonged, acute pain, but rather a series of underlying (long-term) physiological changes to sensory neurons that cause pain even after the inflammatory response and crisis have resolved due to inadequate treatment (Jacob & Mueller, 2008).

2.1.3 Clinical Treatments of Sickle Cell Disease

Sickle cell crises are characterized by complaints of chronic pain and swelling in the abdomen, back, joints, extremities, and chest that vary in frequency, intensity and duration, and fatigue (Rees et al., 2003; Bennett, 2005; Logan, Radcliffe, & Smith-Whitley, 2002; Shapiro et al., 1995). Every child with SCD experiences pain associated with the disease at some point (Houser et al., 1992); however, the pain and severity varies within and across individuals, and is the result of a poorly understood, complex interaction between biological and psychosocial factors (McClish et al., 2006; Fuggle et al., 1996; Shapiro et al., 1995), mediated by neurophysiologic mechanisms, subjective experiences, and behavior response of the individual, attitude of others in the environment, cultural variables, age and developmental level of the child, as well as the individual's belief in the efficacy of the treatment and his or her own ability to control the pain (Houser et al., 1992). The repeated and unpredictable nature of pain crises can be a significant problem for individuals with SCD, as chronic pain affects the individual's quality of life and the frequency of these painful episodes can affect mortality. Studies have found that individuals with high rates of pain have a higher tendency to die earlier than those who report low rates of pain (Bennett, 2005; Anie, 2005).

Sickle cell disease is not directly life threatening; however, inappropriate treatment of the disease and the chronic pain associated with this condition may result in unnecessary suffering and potentially fatal complications. Studies indicate that repeated admissions to the hospital are associated with higher morbidity and mortality rates (Rees et al., 2003); pain crises are the primary reason for frequent hospitalization and some patients may require as many as 40 hospital admissions per year due to the pain associated with SCD (Houser et al., 1992). Pain crises generally indicate the manifestation of an underlying condition(s); patients should initially be

assessed to detect the presence of fever, infection, dehydration, acute chest syndromes such as dyspnea (shortness of breath), tachypnea (rapid breathing), and chest pain, severe anemia, cholecystitis (inflammation of the gall bladder), spleen enlargement, weakness or loss of function in the extremities, abdominal pain, stroke, and/or priapism, as these conditions could be life-threatening if overlooked (Rees et al., 2003; Houser et al., 1992; Ellison & Shaw, 2007).

The clinical goal of treating SCD has remained virtually unchanged for the last 20 years and consists of modifying the source of pain, interrupting the transmission of pain, and altering the perception of pain (Wang, 2002), while preventing complications associated with the disease (Houser et al., 1992; Gil et al., 1989; Ellison & Shaw, 2007; Geller & O'Connor, 2008). For most, there is no cure for SCD; however, bone marrow transplants offer a potential cure but often are not pursued due to the high risk of morbidity and mortality of the procedure, however, gene therapy show significant promise as a preventative strategy (Mitchell et al., 2007). Non-specific treatments used to prevent the complications associated with SCD include penicillin, vaccines, folic acid supplementation, routine blood transfusions, and various drugs such as hydroxyurea and droxia (Houser et al., 1992; Creary, Williamson, & Kulkarni, 2007; Yoon & Black, 2006; Mitchell et al., 2007). Other drugs have been developed to treat SCD but have been found to be either ineffective or hazardous in vivo (Houser et al., 1992).

A specific set of criteria is used to classify pain severity as mild, moderate, or severe in order to determine the proper mode of treatment, as there are no biomarkers to indicate pain severity; the pain is measured subjectively (Ellison & Shaw, 2007). Clinical management of pain includes hydration (intravenously in severe cases), heat, and/or analgesic therapy (oral, intramuscular, or intravenously depending on severity) (Mitchell et al., 2007). The goal of analgesic therapy is to provide optimal pain relief with minimal side effects, according to the

World Health Organization's Pain Ladder. When pain occurs, the mildest form of pain medication (acetaminophen) should be promptly administered first; if pain cannot be alleviated, stronger pain medications should be administered, such as non-steroidal anti-inflammatory medication (aspirin) and opiates (codeine, oxycodone, and morphine) (Wang, 2002; Rees, 2003; Houser et al., 1992; Geller & O'Connor, 2008). In 2002, the National Health Institute (NIH) published a document that contained guidelines for the clinical management of SCD as follows: (1) Rapidly administering analgesic therapy (within 15-30 minutes of arrival); (2) Using an appropriate starting dose; (3) Repeating the dosage every 15-30 minutes until the pain is controlled; and (4) Selecting a treatment regimen based on individualized analgesic therapy history.

2.1.3.1 Physician Knowledge of Opioid Treatment

Clinicians often regard SCD pain as being acute or acute recurrent pain; however, the pain associated with SCD is more accurately designated as chronic or chronic recurrent pain (Shapiro et al., 1995). Solomon (2008) found that most medical textbooks do not provide adequate information about the severity, treatment, and prevention of pain in individuals with SCD nor do they provide reassurance about the unlikelihood of opioid addiction within this population. Most physicians are not aware of opioid guidelines nor of treatment recommendations and clinical decisions about whether children experience pain as intensely as adults. As a result, pain management therapies are based primarily on the physician belief versus scientific evidence. Consequently, many children receive minimal analgesic therapy, causing them to suffer needlessly and increasing the risk of opioid addiction (Yoon & Black, 2006; McGrath & Ruskin, 2007), as individuals with SCD are twice as likely to become opioid-dependent than other pain patients in the emergency department (Solomon, 2008). According to

Geller and O'Connor (2008), children with SCD who receive inadequate pain management develop a pseudo-addiction rather than an actual addiction to opioids, as they continuously seek pain medication and exhibit addictive behaviors; however, these addictive behaviors resolve once adequate analgesic therapy is achieved, which is uncharacteristic of true addiction (Solomon, 2008; Geller & O'Connor, 2008).

Despite the impact of chronic pain on children, we lack child-specific data about the efficacy of pharmacological treatments used to manage chronic pain; as a result, almost all drug therapies used to treat childhood chronic pain are derived from adult data, which can cause serious damage to the child's developing systems and increases the risk of overdosing (Eccleston & Malleson, 2003; McGrath & Ruskin, 2007). A study conducted by Mayor (2008) found that insufficient care provided by inexperienced medical staff using opioids to treat pain related to SCD was a major problem, as many individuals who were admitted to the hospital with chronic pain died of an overdose (Solomon, 2008; Mayor, 2008). This results as a lack of definitive epidemiologic data regarding personal and economic costs associated with childhood chronic pain as well as prevalence, natural history, and impact of chronic pain on the lives of children and their families; thus, appropriate funding is limited to address chronic pain in children (Yoon & Black, 2006; McGrath & Ruskin, 2007; Martin et al., 2007). Despite a lack of funding, many studies have documented an association between chronic pain and impairment of physical and psychological functioning and loss of productivity in activities of daily living in childhood that carry into adulthood (Nguyen, 2005; Green et al., 2004; Farrell, Wicks, & Martin, 2004).

According to the Centers for Disease Control and Prevention (CDC) (2007), SCD can be effectively managed through systematic and multidisciplinary approaches to preventing and monitoring pain in children with SCD (Creary, Williamson, & Kulkarni, 2007). Thus, the

treatment of chronic pain in children with SCD has begun to shift from a disease-specific focus concentrating on a physical diagnosis, to a child-centered focus using interdisciplinary pain management teams to address psychosocial factors that influence or contribute to childhood pain (Martin et al., 2007). Studies have demonstrated that integrating physical, psychological, and behavioral health and pharmacological and non-pharmacological approaches to pain management such as relaxation, guided imagery, massage, diversion, heating pads, hypnosis, and bed rest may result in more positive health outcomes than each method individually. However, there are only a handful of well-controlled trials of behavioral and non-pharmacological management of SCD (Wang, 2002; Mitchell et al., 2007; Ellison & Shaw, 2007) that focus on complementary therapies for children with SCD, despite recommendations from the American Pain Society (Yoon & Black, 2006). Multidisciplinary approaches to treating SCD related pain that incorporate psychosocial and behavioral components have been found to be more effective and appear to reduce hospitalization and emergency room visits (Gil et al., 1989), resulting in decreased morbidity, mortality, and disability for those plagued by this illness (Anie, 2005). Thus, morbidity, mortality, and disability associated with sickle cell disease, and other chronic illnesses, are potentially modifiable with optimum pain and disease management which can significantly reduce the risk of chronic pain and psychological problems in children that can be carried into adulthood (Farrell, Wicks, & Martin, 2004; Palermo & Chambers, 2005).

2.2 SELF-CARE MANAGEMENT OF SICKLE CELL DISEASE

2.2.1 Self-Care Among Chronically Ill African Americans

Self-care is defined as the health and illness behaviors individuals, families, and communities exhibit, on behalf of their own health, in order to prevent disease and alleviate symptoms and illnesses (Becker, Gates, & Newsom, 2004). According to Becker, Gates, and Newsom (2004), almost 70% of African-Americans practice self-care as a result of low socio-economic status that leads to a lack of health insurance, dissatisfaction with the health care system, and problems paying for medical bills and prescriptions, yielding disproportionate rates of disease and premature death among African-Americans (Becker & Newsom, 2003; Becker, Gates, & Newsom, 2004). On the contrary, Sibinga et al. (2006) found that very few African-Americans practiced self-care behaviors and those who did had older parents or serious medical conditions (Sibinga et al., 2006).

Self-care behaviors of African-Americans are based on African-American culture: beliefs, values, and widespread practices of spirituality, social support and advice, as well as traditional medicine. Self-care behaviors are typically acquired during childhood and transmitted inter-generationally throughout the family structure and affect how caregivers perceive and manage a child's illness; how health services and treatments are used; and how information is received, processed, and used (Becker, Gates, & Newsom, 2004; Farrell, Wicks, & Martin, 2004; Sterling, Peterson, & Weekes, 1997). Religion, spirituality, and relaxation are the most commonly used forms of self-management among African-Americans in order to cope with SCD and chronic illnesses and have been shown to improve health outcomes (Sibinga, 2006; Yoon &

Black, 2006; Harrison et al., 2005). Other forms of self-care management among African-Americans include diet, herbal/home remedies, massage, and warm baths (Sibinga et al., 2006).

2.2.2 The Theory of Self-Care Management for Sickle Cell Disease

The Theory of Self-Care Management for Sickle Cell Disease (SCMSCD) was derived from the Theory of Self-Care Management for Vulnerable Populations and suggests that vulnerability factors such as socio-economic status and health needs have a negative impact on both health outcomes and self-care management. The theory suggests that providing self-care management resources to individuals with SCD and their caregivers is an effective way of positively mediating the relationship among vulnerability factors, negative health outcomes and poor self-care management among individuals at risk for health disparities. Self-care management resources include SCD education; developing positive coping behaviors; establishing social support; increasing self-efficacy and self-care action(s) among parents and children; improving assertiveness within the health care system and enhancing physician-patient and parent-child communication skills (Jenerette & Murdaugh, 2008). A study conducted by Jenerette and Murdaugh (2008) found that self-care management resources enabled individuals dealing with SCD to maintain control over and manage day-to-day and life-long needs of SCD disease and improved their access to health care resources, ultimately improving the health status and quality of life of children with SCD.

2.2.2.1 Vulnerability Factors Affecting Individuals with Sickle Cell Disease and Their Families

Vulnerability refers to the likelihood of experiencing poor health as a result of individual and ecological factors that determine access to and utilization of health care services. In the SCMSCD, vulnerability factors include socio-demographic characteristics (age, income, education, employment) and health need factors (disease complications) associated with SCD that influence the health status and quality of life of individuals with SCD. The complex interaction among multiple vulnerability factors is responsible for negative health outcomes associated with SCD (Jenerette & Murdaugh, 2008), as African-American children with a chronic illness have higher pain severity and disability when compared to Caucasians and older African-Americans (Green et al., 2004).

Caring for a child with a chronic illness is often associated with financial strain and limited resources, which contributes to poor pain management; sickle cell disease is no exception (Becker & Newsom, 2003). Families with low socioeconomic status, regardless of ethnicity and specific illness, are strained by their social and economic conditions thereby limiting resources, which often impedes the family's ability to effectively cope with and manage their child's disease, resulting in more negative health outcomes and higher utilization of health care services when compared to families with higher socio-economic status (Kaslow & Brown, 1995; Ellison & Bauchner, 2007). Furthermore, children born into low-income families are more likely to be admitted to the hospital, have longer hospital stays, and generate higher costs during the first 10 years of life compared to children born into more advantaged families (Ellison & Bauchner, 2007).

Among low-income African-American families, sickle cell individuals more often reside in single parent families, with female heads of household dependent on welfare, as many African-American children with low socioeconomic status do not live with their biological fathers; to complicate things further, many children with SCD in low-income, African-American families are born to teenage mothers. Consequently, these families exhibit higher rates of father absences, resulting in single mothers as the primary caretakers of children with sickle cell disease, as African-American women value being a mother more than a partner (Kaslow & Brown, 1995). These mothers are usually actively involved in the work force and the community, which oftentimes leaves the child(ren) to assume the parental role within these families; assumption of this role is typically accompanied by higher levels of family responsibilities and a diminished capacity for nurturant and consistent parenting, as well as lower levels of resources (Kaslow & Brown, 1995). As a result, single mothers often rate their relationship with their child as poorer than do two-parent families, and are more likely to experience stress associated with the burden of caring for a child with SCD, compared to other parents (van der Tweel et al., 2008). Barakat et al. (2008) found pain rating discordance among children/adolescents with SCD and their caregivers in low-income families; this is a serious problem as Mitchell et al. (2007) found that parents rely on their children to monitor their own symptoms, tell them when they are experiencing pain, and provide them with directions and requests for treatments regarding their condition. Parents of children and adolescents with SCD acknowledge their inability to cope and make decision about their child's illness independently (Mitchell et al., 2007), which contributes significantly to maternal and child stress and poor subjective health perceptions in both children with SCD and their caregivers (Logan, Radcliffe, & Smith-Whitley, 2002; Barakat et al., 2008; van den Tweel, 2008).

Due to the daily demands, responsibilities and stress associated with caring for a child with SCD, single mothers and their children often require more support and guidance regarding pain management in order to improve their quality of life (Barakat et al., 2008), which motivates caretakers to seek support from their extended families (Sterling, Peterson, & Weekes, 1997) to effectively cope with their child's illness. African-Americans include in their families relatives (blood related and non-blood related), friends, and community members living in close proximity to one another and share many common experiences (Kaslow & Brown, 1995). Regardless of whether the father is present or not, African-American extended family networks have been found to provide significant support to caregivers of children with SCD. Sterling, Peterson, and Weekes (1997) found that African-American mothers were more effective primary caretakers when they perceived themselves as being supported by their extended family network, as extended family members often alleviated maternal stress by performing household chores, preparing meals, and providing transportation, childcare, and supplemental income through loans, collections, or monetary gifts. Historically, African Americans have sought support and guidance from relatives, friends, and community members, as many African Americans distrust and/or lack information about services from the health care system due to racism and discrimination. Mothers of children with SCD have reported that they exhibit higher stress levels due to this lack of information about how to care for their child with SCD (Kaslow & Brown, 1995).

Mistrust of and dissatisfaction with health care are deterrents to seeking care. Persons with low socioeconomic status tend to be Medicaid recipients or are uninsured, have poor quality health care, seek health care less often, and seek care only in the event of an emergency because of the difficulties low-income families often encounter in accessing care. These individuals do

not have consistent follow-up for health problems and are infrequently seen for routine checkups. Routine checkups serve as a primary vehicle for helping patients to understand and manage chronic illnesses; however, low-income patients reported that they felt that their physicians were inattentive to their problems, were condescending, did not explain things thoroughly, and/or brushed off their queries. Thus, many low-income families questioned their physician's knowledge and skills, in addition to wondering whether they were receiving good health care, which reinforces mistrust in the health care system (Becker & Newsom, 2003; Nguyen et al., 2005). Patients and their families have characterized the medical community as being "tolerable" and that they experience adverse relationships with their health care providers (McClain & Kain, 2007).

Vulnerability of Adolescents with Sickle Cell Disease

Adolescence is a transition period for teenagers into adulthood, characterized by physiological, personal, and social maturation. This transition is particularly challenging and stressful for teenagers with SCD, as they cope with the day-to-day issues and secondary complications (delayed puberty and sexual maturation) associated with their illness (Gil et al., 2003). As a result, adolescents with SCD are psychologically vulnerable due to high stress levels, which may lead to feelings of inadequacy, insufficiency, anxiety, depression, and negative moods. The development of psychological problems has been found to increase pain severity, which in turn yields increased school absences, increased health care utilization, social isolation, and poor quality of life (Gil et al., 2003; Merlijn et al., 2006). Studies have found that an association exists between high stress levels, negative mood, and severity of pain and that psychosocial factors have been found to mediate this relationship (strengthen or weaken); adolescents with the ability to cope with pain and adapt to their daily routines have a better

quality of life versus adolescents who are unable to cope with and adjust to their daily routines (Merlijn et al., 2006).

Additionally, Logan, Radcliffe, and Smith-Whitley (2002) concluded that adolescents may be vulnerable to developing life-long patterns of poor health service usage as a result of insufficient coping strategies on the part of the parents. The Risk-Resistance-Adaptation Model indicates that adaptation during adolescence can be mediated by risk factors (disease severity and poor coping strategies) and resistance factors (social-ecological situation and demographics); furthermore, improved adaptation mediates the illness outcome and demographic factors of individuals with SCD, based on the Transactional Stress and Coping Model, which reduces the risk of developing risk and resistance factors that are often acquired during adolescence. During adolescence, individuals with SCD begin making decisions and exerting control over use of health care services, which has been found to be influenced by parental characteristics rather than the actual severity of the disease; thus, children and adolescents are at risk for developing poor disease adaptation due to social-ecological factors, poor parental coping strategies, and disease management combined with complications of their disease, potential psychological problems, and the stresses of transition into adulthood (Logan, Radcliffe, & Smith-Whitley, 2002). Healthy adjustment during childhood has been found to decrease vulnerability during adolescence as well as in adulthood (Anie, 2008; Yoon & Black, 2006).

2.2.2.2 Health Outcomes of Individuals with Sickle Cell Disease and Their Families

According to Sterling, Peterson, and Weekes (1997), 246.5 of every 1,000 African-American children have a chronic illness; the most prevalent illnesses include asthma, eczema, heart disease, and sickle cell disease. Chronic pain is a major public health problem among African-American children with SCD as it hinders the goal of Healthy People 2010, to ensure

that quality health and long life are enjoyed by all by the year 2010 (Farrell, Wicks, & Martin, 2004). SCD impairs the health and well-being of these children with its significant physical, psychological, emotional, and socioeconomic implications, which have a negative impact on quality of life; defined as physical, psychological, emotional, and socioeconomic well-being (Merlijn et al., 2006; van den Tweel et al., 2008). Poor quality of life is associated with poor relationships with health care providers and poor coping, adjustment, and disease management among both caregivers and children with SCD (Anie, 2008).

Chronic pain in individuals with sickle cell disease can be exacerbated by failed attempts to adjust and cope with the uncontrollable and unpredictable nature of the disease. Coping is the (multi-dimensional) process of dealing with the illness-related stress associated with chronic illnesses, as children with sickle cell disease require lifelong disease management (Sterling, Peterson, & Weekes, 1997). Studies show that individuals with sickle cell disease lack appropriate pain coping strategies, which reduces their quality of life by placing restrictions on their daily functioning (Anie, 2008; Yoon & Black, 2006). The extent to which individuals are affected by their disease may be determined by their coping responses, as dealing with the continuous demands of sickle cell disease requires the acquisition of new skills and modification of daily life (Anie, 2008). Failure to properly cope with or manage this intense physical pain increases the risk of developing psychological problems (Sterling, Peterson, & Weekes, 1997) including depression, anxiety, attention deficit/hyperactivity disorder, adjustment and interpersonal difficulties, maladaptive cognitions, withdrawal, aggression, poor relationships, low self-esteem, poor academic performance, and neurocognitive impairments (Anie, 2008; Kaslow & Brown, 1995; Yoon & Black, 2006).

Quality of Life Issues Among Caregivers of Children with Sickle Cell Disease

Research suggests that having a child with a chronic illness is a significant stressor among caregivers, as young children with chronic illnesses depend on their caregivers to care for and monitor their illness and to understand their pain (McGrath & Ruskin, 2007; Sterling, Peterson, & Weekes, 1997). The quality of care that children with SCD receive may be affected by the caregiver's well being, as the unpredictable course of the disease requires immediate care and places heavy physical, emotional, and financial demands on caregivers. According to van den Tweel et al. (2008), the challenges of caring for a child with SCD has been described as a "burden" among caregivers of children with SCD, as caregivers are responsible for the day-to-day management of their child's illness: administering medication, recognizing and treating SCD related complications, and preventing crises. The unpredictability and uncontrollability of vaso-occlusions may require hospitalization that interferes with the caregiver's work schedule, leisure activities, other family member's schedules, and financial complications due to travel expenses and hospital costs (van den Tweel et al., 2008; Logan, Radcliffe, & Smith-Whitley, 2002). Parents reported that "SCD impacts personal and family life, including friendships, employment, schooling, participation in activities, and family activities and relationships including interactions and quality time with siblings" (Mitchell et al., 2007). Additionally, caregivers of children with SCD, primarily mothers, are plagued by the emotional burden of confronting their child's pain, refusal to accept the child's diagnosis/prognosis, anxiety about the child's future, marital strain, depression and feelings of guilt as SCD is an inherited disease, and lack of professional and social support (Logan, Radcliffe, & Smith-Whitley, 2002; van den Tweel et al., 2008; Sterling, Peterson, & Weekes, 1997).

Good health, positive coping strategies, and quality of life are important among caregivers of children with SCD as these factors affect their health and quality of life. Several studies have found that 30-40% of caregivers displayed symptoms of psychological distress as well as an impaired quality of life, compared to caregivers of healthy children (Logan, Radcliffe, & Smith-Whitley, 2002; Kaslow & Brown, 1995; Sterling, Peterson, & Weekes, 1997). Additionally, children with SCD recognize the burden associated with their illness which contributes to poor adjustment, psychological problems, and negative health outcomes (Logan, Radcliffe, & Smith-Whitley, 2002; Sterling, Peterson, & Weekes, 1997). Caretakers serve as role models for children, which influences or interferes with the child's ability to cope with and adjust to the chronic illness (Sterling, Peterson, & Weekes, 1997). Lifelong patterns of unmanageable pain and overuse of the health care system begin in childhood and adolescence as a result of the caregiver's inability to properly cope with and manage the child's disease; thus, it is important to facilitate healthier adjustments and demonstrate appropriate coping behaviors and health care utilization for pain management to occur early in childhood (Logan, Radcliffe, & Smith-Whitley, 2002).

2.2.2.3 Self-Care Management Resources for Individuals with Sickle Cell Disease and Their Families:

In the past two decades, behavioral scientists have made major contributions to the assessment and treatment of acute and chronic pain problems in individuals with SCD (Gil et al., 1989). Interventions aimed at improving assertiveness, self-efficacy, coping behaviors, social support, self-care abilities and actions, and communication skills (self-care management resources) among children with SCD and their caregivers have been shown to increase life expectancy, decrease health care costs associated with SCD, and improve quality of life. As a

result, self-care management resources have become one of the primary foci of SCD research and practice. Kaslow and Brown (1995) suggest that African-American families with a child with a chronic illness require self-care management resources that educate parents about caring for a child with SCD and teach them to effectively communicate with and navigate the health care system (Kaslow & Brown, 1995), as SCD disease is primarily managed at home and inadequate home management of SCD due to inadequate self-care is associated with poor health outcomes and quality of life (Anie, 2008; Barakat et al., 2008; Panepinto, 2008; Jenerette & Murdaugh, 2008).

Self-Care Management Resources & Sickle Cell Disease: A Brief Review of the Literature

In order to provide adequate home management, caregivers and children must be knowledgeable about SCD, its pathophysiology and clinical manifestations, recognize signs and symptoms of crises and other life-threatening events, in addition to acquiring the skills to effectively cope with, manage, and treat the disease within this environment. Parents who understand their child's illness are more confident in their ability to care for and manage the disease, facilitate positive coping and adjustment to the complications associated with SCD, and adhere to routine services and clinical recommendations versus seeking emergency care (Logan, Radcliffe, & Smith-Whitley, 2002; Houser et al., 1992; Barakat et al., 2008). However, several studies report that caregivers are uneducated about SCD and its treatment and lack self-efficacy and positive coping behaviors to adequately manage SCD in the home setting (Houser et al., 1992; Barakat et al., 2008) due to insufficient information and education provided by the medical centers.

Routine services are the primary vehicle for providing individuals with information regarding knowledge, skills, and lifestyle modifications required to care for a child with SCD. Koontz et al. (2004) found that caregivers of children with SCD who relied on routine services for information about their child's illness were misinformed and displayed serious knowledge deficits regarding the special needs and physical manifestation of SCD and its adverse health concerns.

Furthermore, many caregivers fail to implement the skills needed to care for a child with SCD because of passive learning, such as reading a pamphlet/brochure (Farrell, Wicks, & Martin, 2004). Active learning has been found to have a profound effect on self-care management skills; Farrell et al. (2004) found that increasing self-efficacy among individuals with or caring for chronic illnesses lead to improved health outcomes. Studies have found that programs that focus on self-efficacy, communication, and education empower parents to take control of and manage their child's condition, in addition to advocating for the best possible care for their child, resulting in improved parent education, clinical practices, and health outcomes of both the child and their caregiver (Farrell, Wicks, & Martin, 2004; Kaslow & Brown, 1995; Houser et al., 1992; Koontz et al., 2004).

One of the responsibilities of health care team of individuals with SCD is to provide the family with a sense of control over its situation (self-efficacy) by aiding them in developing appropriate coping strategies and alternative pain management techniques (Houser et al., 1992). In order for health care providers to effectively intervene and convey this information to patients and their caregivers, they should have an understanding of the child's social-economic environment as well as African-American culture, in addition to being knowledgeable about SCD and its potential adverse conditions (Kaslow & Brown, 1995). Oftentimes, health care

providers fail children with SCD and their families through poor communication and misunderstandings regarding vital information (Houser et al., 1992; McGrath & Ruskin, 2007). Furthermore, health care providers have admitted that individuals with SCD and their caregivers are difficult to communicate with; they exhibit difficulty communicating information in a manner that is understandable by the caregiver; and that caring for the child's illness is challenging due to the caregiver's culture including values, beliefs, and language discordance (Thomas & Cohn, 2006; Ashton et al., 2003). As a result, critical information may never be presented to the child's caregiver (Houser et al., 1992). Consequently, patients and caregivers are often not involved in the decision making process regarding treatment, leading to suspicion among caregivers and patients that strengthens their mistrust with the health care system and contributes to racial and health disparities (Thomas & Cohn, 2006; Bennett, 2006; Sterling, Peterson, & Weekes, 1997).

Parents have reported that negative health outcomes associated with SCD are exacerbated by the lack of information and miscommunication provided by the health care system (Sterling, Peterson, & Weekes, 1997). When asked about their specific needs, parents indicated that they wanted additional familial, professional, and financial support and personal guidance, as well as additional educational resources that "break down" information about SCD, how to cope with caring for a child with SCD, and how to access available services offered to individuals with SCD and/or chronic illnesses (Bennett et al., 2006; Mitchell et al., 2007; van den Tweel et al., 2008; Sterling, Peterson, & Weekes, 1997). Additionally, parents expressed a preference for using their social networks for support and acquisition of information as they perceive health personnel as being racist, providing inaccurate information, and being insensitive to their needs (Sterling, Peterson, & Weekes, 1997).

According to Treadwell, McClough, and Vichinsky (2006), the primary sources of information acquisition among African-Americans are family, friends/acquaintances, magazine articles, television ads, and brochures from local health departments or community agencies. Targeting African-Americans' informal networks has been recommended to increase education and awareness about SCD; however, receiving information from a community organization was found to be the best source of information to provide African Americans with information about SCD (Treadwell, McClough, & Vichinsky, 2006). Community organizations' services and information are utilized by individuals with SCD and their caregivers as this information is perceived as being trustworthy and contributes to their ability to cope with the disease and reduces stress by offering emotional support and sometimes financial support (Bennett, 2005; Treadwell, McClough, & Vichinsky, 2006). Both parents and health care providers agreed that more educational information should be available within the community and have suggested that information be available for children in grade school through college, in addition to offering activities that allow children with SCD to interact with one another, in order to educate them about their condition (Treadwell, McClough, & Vichinsky, 2006; Mitchell et al., 2007). Thus, further research needs to be done in order to develop age-appropriate materials and interventions for caregivers and children with SCD in order to provide information about their specific needs (Houser et al., 1992).

3.0 PARENT ADVOCACY TOOLKITS

The Children's Sickle Cell Foundation is planning to develop Parent Advocacy Toolkits that contain self-care management resources. Health communication strategies will be used to determine the self-care management resources to be included in the toolkits.

3.1 THE CHILDREN'S SICKLE CELL FOUNDATION, INC.

The Children's Sickle Cell Foundation, Inc. (CSCF) is a non-profit organization located in Mount Washington, Pennsylvania, that is committed to providing quality programs to children and families affected by sickle cell disease (SCD) in the Pittsburgh area. CSCF was established in 2004 by a group of parents of children with SCD and other community members with an interest in the well-being of these children and their families. To our knowledge, CSCF is the only community-based organization in the United States providing services for children (18 year of age and younger). The Executive Director of CSCF, Ms. Andrea Williams, and her Board of Directors have made it their mission at CSCF to provide social, educational and economic support for children with SCD and their families, with sickle cell trait outreach and support for SCD research as natural extensions of this mission, in order to improve their quality of life. This mission was derived from the overarching goal of Healthy People 2010, "To ensure that quality

health and long life are enjoyed by all by the year 2010,” (Farrell, Wicks, & Martin, 2004) in order to meet the specific needs of the families that CSCF serves.

CSCF’s Educational Support Program is one of the products of this mission, which was originally designed to improve academic achievement among children with SCD. SCD is considered to be a chronic illness and a considerable amount of research suggests that children who have chronic illnesses are at risk for poor academic achievement (Koontz et al., 2004). Children with SCD are plagued by unpredictable episodes of pain that can disrupt their academic performance, as these children typically exhibit frequent absenteeism and neurocognitive deficits associated with this disease that contribute to learning problems (Koontz et al., 2004; Shapiro et al., 1995; King et al., 2006), which may require the child to be retained a grade or placed in a special education classroom (King et al., 2006). Additionally, the inability to manage school work may yield a pattern of school avoidance which may result in failure to graduate, which may have an impact on potential employment opportunities and ultimately their quality of life. Despite the impact SCD has on academic achievement, many students may not qualify for homebound assistance in some states, as students must miss a maximum number of consecutive days to be qualified for assistance and children with SCD do not meet this criteria. Thus, these children are typically overlooked for interventions because, unlike children with other chronic illnesses, the impact of SCD on the child’s academic performance may not be recognized by health care professionals (Shapiro et al., 1995). Therefore, CSCF created its Education Support Program to address this problem in an effort to improve the academic performance of children with SCD in the Pittsburgh area.

This program is a collaborative effort between CSCF, Children’s Hospital of Pittsburgh Sickle Cell Program, and the Pittsburgh Public School System designed to assist children with

SCD in maintaining continuity in their education when they are absent from school due to their illness, while ensuring that every child with SCD receives the proper support to encourage their educational success. Children are enrolled in the program after an introduction has been made by Children's Hospital Pittsburgh (due to HIPPA) during well child visits or in the event that the child is hospitalized for complications associated with the disease. Once the child is enrolled, CSCF contacts the child's teacher and school counselors to make the necessary arrangements to retrieve the student's assignments and transport them to the child's home (or the hospital) within 24-36 hours in the event that the child will be absent from school. CSCF also provides laptops and other resources for the children to ensure that students are able to complete their school work, in a timely manner, to prevent them from falling behind academically. Once the children are enrolled in this program, they become part of the CSCF family and are eligible to participate in other programs and events offered by CSCF including: Swim Program, Read 2 Lead, Back 2 School Bash, and the Motor-Sickle Awareness Ride.

Through these programs, CSCF has identified a lack of education among the families that they serve, as caregivers have voiced a need for additional information about their child's condition, about how to properly manage the disease at home, and to receive adequate information from health care teams. These findings are consistent with several studies conducted by the Cincinnati Children's Hospital Medical Center that found that routine services are not sufficient in providing educational information to children with SCD and their caretakers. Caregivers who relied on routine services had only a basic understanding of disease etiology and management and exhibited serious knowledge deficits regarding the physical sequelae of the disease, signs and symptoms of adverse, life-threatening health outcomes, and the special needs of an individual with SCD that could negatively impact their quality of life (Koontz et al., 2004).

As a result, studies recommend increasing parental knowledge of SCD, in addition to developing age-appropriate materials for children, as well as their caretakers, that address these needs as a way of empowering the parents to advocate for the best possible care for their child (Koontz et al., 2004).

Based on these recommendations, CSCF is planning to develop Parent Advocacy Toolkits that contain age-appropriate, self-care management resources for caregivers of children with SCD that include additional SCD education, as well as positive coping and disease management behaviors, social support resources, self-efficacy and self-care action information, which are not provided through routine services, for caregivers of children in different developmental stages of life (Jenerette & Murdaugh, 2008). Consequently, further research needs to be done in order to develop age-appropriate materials for children, as well as their caretakers, that address the needs identified by this community.

3.2 HEALTH COMMUNICATION

Health communication is the study and use of methods to inform and influence decisions and behaviors that affects an individual's and community's health (Freimuth & Crouse Quinn, 2004). Utilizing health communication strategies to develop and implement self-care management resources will empower the parents to advocate for the best care for their child. It cannot compensate for a lack of access to health care and or other vulnerability factors; however, it is an effective and efficient method of reducing health disparities and poor health outcomes among

families caring for a child with SCD. Studies have shown that appropriate health communication resources have the ability to increase knowledge and awareness of SCD; problems and solutions associated with SCD; influence families' perceptions, beliefs, behaviors and attitudes regarding SCD/self-care management and the health care system; improve physician-patient relations and adherence to clinical recommendations; and educate families about how to gain access the health care system and when/how to use the health care system (Healthy People 2010; Freimuth & Crouse Quinn, 2004).

The self-care management resources to be included in the Parent Advocacy Toolkits will be identified and developed using the Health Communication Program Cycle (HCPC). The HCPC consists of four phases (1) Planning and Strategy Development; (2) Developing and Pretesting Concepts, Messages, and Materials; (3) Implementation; and (4) Assessing Effectiveness and Making Refinements. For the purposes of this paper, the Planning and Developmental Phase consists of (1) Assessing where caregivers received self-care management resources; (2) Reviewing existing self-care management resources to determine what type(s) of information have already been acquired; (3) Learning about the type(s) of self-care management resources that intended audiences need; and (4) Exploring the most appropriate channels with which to disseminate self-care management resources (National Cancer Institute, 1989). The results of this phase will be used to create a strategic plan to develop the Parent Advocacy Toolkits and serve as the foundation for the subsequent phases of the HCPC.

4.0 THE STUDY

This study was approved by the University of Pittsburgh's Institutional Review Board (IRB) on October 8, 2008 (A replication of the IRB Approval Letter for protocol # 08090555 can be found in the Appendix A).

4.1 METHODOLOGY

Focus groups are an appropriate method of data collection to obtain information from minority groups that may be culturally and/or linguistically diverse (Krueger, 2006). A focus group is a facilitated interview technique used in qualitative research to address specific questions through group discussions, based on the premise that the respondents are a valuable source of information. By listening to these individuals we can glean information about knowledge, perspectives, and attitudes regarding a particular topic, issue, or experience (Halcomb et al., 2007). Focus groups are unique in that the moderator (or interviewer) asks questions to an entire group, versus individually, which permits respondents to interact with one another to exchange ideas, feelings, thoughts, comments, and different points of view about their experiences (Wong, 2008; Krueger, 2006). Conducting a focus group involves recruiting participants, facilitating group discussion, transcribing the discussion, data analysis, and reporting the findings (Wong, 2008).

4.2 PARTICIPANT RECRUITMENT

Potential participants were identified from the Education Support Program roster at the Children's Sickle Cell Foundation, Inc (CSCF). This was done by the author, who served as an intern at the foundation and worked with the families. Eligibility requirements were (1) the caregiver had to live with the child with SCD and served as the primary caregiver of a child with SCD during the previous 12 months; and (2) the child with SCD has to be enrolled in the Education Support Program and participated in two or more of the program/events offered by CSCF during the past 18 months. This criteria was used to ensure that there would be enough caregivers to conduct a single focus group. Eligible caretakers were contacted via letters, telephone calls, and in-person during CSCF events to participate in a focus group. All eligible caretakers were originally mailed a letter from the Children's Sickle Cell Foundation, Inc. (See Appendix B) indicating their eligibility. The letter also provided the parents with a brief overview of the study, where the study was to be held and the incentives for families that participate.

Approximately one week after the letters were mailed, the caretakers were contacted via telephone or contacted the foundation, upon which time the study was described in greater detail according to the designated telephone script (See Appendix B). The telephone script contained informed consent information so that the parents could make an educated decision about whether to participate in the study or not. Reminder calls were made the day before the focus group to confirm participation, the time, and location of the events.

4.3 ANALYSIS

The audio tapes from the focus group were transcribed verbatim by the author into Microsoft Word 2007. The transcription reflected the participants' grammar, pauses, nuances, and unfinished sentences; however, some editing was done in order for the transcripts to be more understandable by the reader. Once the transcript was completed, the audio tape was played in its entirety and the transcript was compared to the audio tape in order to confirm that the transcript accurately reflected the discussion recorded during the focus group. The script was corrected as needed and compared to the full length audio taped discussion, once again, until it accurately portrayed the discussion (See Appendix D).

The questions from Moderator's Guide served as a template to generate a table to be used to formulate the results of the discussion pertaining to that particular question. The themes that emerged from the focus group discussion, as well as the themes the found in the literature were recorded in the rows next to the question topic. The themes from the focus group and the pre-existing literature were compared to formulate conclusions about the needs of the families to be addressed through the Parent Advocacy Toolkits. Furthermore, quotations from the transcripts of the focus group were included into the table in order to support the themes that were identified during the analysis.

5.0 RESULTS

A focus group was conducted with the caregivers of children with SCD on Saturday, October 25, 2008 at 1:30p.m. at Atria's Restaurant. This location was chosen due to its close proximity to Funfest, one of the incentives for participation, and its private dining rooms. Based on the inclusion criteria, ten families were eligible to participate in the focus group. Of these ten families, six agreed to participate in the study yielding 10 total participants (seven mothers, two fathers, and a grandmother). The other six families were unable to attend due to long distance travel or previous commitments. The focus group was held at the restaurant, in a private room that accommodates 10-17 individuals, where the focus group began with a meal to facilitate group cohesion, social interaction, and generate discussion amongst the caregivers.

The meal lasted approximately 90 minutes as a result of very emotional introductions, as the parents began to share their experiences of caring for a child with SCD. The caregivers went around the room and one-by-one introduced themselves as their child's caregiver and shared a personal story. These introductions were very powerful as the caregivers began to acknowledge their lack of education and misinformation about SCD, which led to their inability to care for their child causing them extreme pain and unnecessary suffering. This generated many tears among the caregivers as they admitted that they ultimately had to acquire information at the expense of their child's health. The caregivers took a few minutes to comfort one another during

this time and expressed their gratitude for the ability to speak with other caregivers, as they indicated that they often felt as if they were the only parent with a child with SCD.

Once the caregivers regrouped, the focus group discussion began and lasted approximately 45 minutes. The discussion was led by the moderator, the Executive Director of the Children’s Sickle Cell Foundation, Inc. and parent of a child with SCD, and began with a brief introduction, during which time the purpose of the focus group and goals of the study were described as well as the principles that guide a focus group and the purpose of audio taping the session. The discussion then proceeded according to the Moderators Guide (See Appendix C) and was audio taped in order to generate transcripts to be used during the analysis phase.

5.1 ASSESSING ROUTINE SERVICE SELF-CARE MANAGEMENT RESOURCES

5.1.1 Where are Caregivers Receiving Self-Care Management Resources?

The focus group began by trying to determine where individuals receive information about SCD. During this discussion, the participants acknowledged that their initial information was provided by Children’s Hospital Pittsburgh Sickle Cell Clinic. As one participant recalls, “I got my first information when I...um, actually, got a book sent to me, they mailed it out from the sickle cell clinic and they sent the book to me...” The information provided by the Sickle Cell Clinic was referred to as, ““That big, thick book that they call the “sickle cell bible....” As the discussion proceeded, it was revealed that some parents had received the “Sickle Cell Bible” while others may not have. One participant stated, “You know, I don’t think that we actually did

receive the book, you know. My son was born, like I said, in 1996. We didn't get a book in 1996," while another parent commented, "We didn't get a book in 2000."

Other sources of information were the internet and from the clinic staff during routine visits. One parent admits,

Periodically, uh...we would get our information from the internet. Just google sickle cell and see what's on...uh, said there but... Primarily all our information comes from the clinic during our visits um over the years we participated in clinical studies, uh, you know Dr. Krishnamurti and crew you know, that's where we get most of our information.

Another mother added, "Most of it [information] didn't come from the Sickle Cell Society to be real honest with you. For me, it was hands on pretty much and asking questions, like always asking questions and probably workin' people's nerves, but just wanting to know."

Another source of information about SCD was also found to be through high school education. The grandmother participating in the focus group discussion stated that, "I got my information before my grandson...prior to sickle cell...before he was born when I was a teenager. I was in certain programs and they discussed sickle cell and that's how the beginning of my information started." Additionally, two mothers from Africa indicated that they received information about SCD "back home." As one mother recounts, "I got mine back home from Nigeria where [there are] more people with sickle cell...So, I got information and idea of what sickle cell is from there..." The second mother concurred, stating, "Yeah, I got the information back in Togo when I was in high school. I studied science so I know about it but I don't know I'm gonna be in this position."

5.1.2 What type(s) of Self-Care Management Resources are Caregivers Receiving?

The “Sickle Cell Bible” and other supplemental information obtained via the internet, clinic visits, or through high school education provide caregivers with general information about SCD and its genetic inheritance. One mother noted,

The first information that I received when I was first diagnosed...well, I really didn't know nothing until they sent me the book. The book explains what sickle cell disease was, where it comes from, it explains what the symptoms are, um...it explains side effects of certain medications that the child might be on, um what the temperature should, should not be and like, every other situation that could possibly go wrong with them, like, it explained everything in that book. If you don't read that book you won't know what, what is going on, that's what I suspect.

Furthermore, another mother commented, “And it also explains that its hereditary, it's not a contagious disease that you get from anybody else, you know from eating or drinking from behind anybody,” while her spouse added, “And it also told, well, we first learned, um, what causes it. Why the pain comes from the limited blood and the blood vessels and all that, but that's some of the original information we got.”

Additionally, the “Sickle Cell Bible” and other sources of information identified during the focus group also provided caregivers with basic information about the child's special needs, signs and symptoms of a sickle cell crisis, and when to take action. As one mother recollects,

I just was going to say I can just remember being told, you know, about some of the warning signs about actually a crisis situation instead of basically...I did get some information, basic information, bits and pieces, of sickle cell disease...and uh...I found out about the hydration and also, you know...pshh... fever, hospital immediately no question. No Tylenol, no nothing straight in...

5.1.3 Are Self-Care Management Resources Helpful in Providing Caregivers with Enough Good Information to Provide the Best Possible Care for their Child?

When asked about how helpful the resources were the responses generated tended to focus solely on information derived from the “Sickle Cell Bible,” not the additional sources identified by the participants. Overall, the “Sickle Cell Bible” was deemed to be not very helpful by the participants, especially during crisis situations. As one father indicated, “That’s a really hard question to answer because when they’re in crisis and you take them to the hospital they’re already in pain, they’re still in pain, and they’re in worse shape because they’re hot up off these drugs and out of it over, behind these drugs.” Other participants also alluded to the fact that the “Sickle Cell Bible” does not provide caregivers with information about what to do during a crisis situation.

The participants agreed that information from the “Sickle Cell Bible,” the internet, and the clinic staff did not provide “hands-on learning,” which was identified by long-term caregivers of a child with sickle cell disease as being more valuable than information from any available source. One of the mothers admitted, ““I would honestly say reading the book, no, it doesn’t [help], but with the hands on experience and you learning your child’s body and knowing what to expect and what symptoms, that is what helps you better than anything as the years go on.” The group agreed that it was “trial and error” that contributed to their knowledge of caring for a child with SCD, versus acquisition of information from the various resources identified. Furthermore, a mother who had previous experience caring for a child with a chronic illness stated, “I feel I do [have enough good information] because I have a child that has sickle cell and I had a child that had leukemia and leukemia is cancer of the blood, so they’re both blood disorders. So, I’m a little bit more educated on what’s going on... ”

On the contrary, a grandmother who serves as a secondary caregiver suggested that information with basic information, like the “Sickle Cell Bible,” would be helpful for other individuals who help to care for children with SCD,

...because I don't have the book at home. So when, when my grandson gets left with me, the book would be helpful to me because the things that I read in the book help me to understand what might be a crisis situation that seems real simple at that moment. See, when they would've taken the child to the hospital, I would be sitting there thinking, if I had more information then I would know if this is the time to go or do I wait a minute or do I try something else? So, the book would be helpful for me because I'm not in it every day. I'm just on the side sometimes and, and that's the hardest part for me, but if I had the book, then I could go look through to that part and that would help me to get through it easier.

5.2 ASSESSING SELF-CARE MANAGEMENT RESOURCE NEEDS

5.2.1 Self-Care Management Resources for New Mothers of Infants with SCD

Of the participants that participated in the focus group, eight of them were primary caregivers of a child three years of age or older, one was a secondary caregiver of a child five years old, and the other was a mother of an infant who had been recently diagnosed with SCD. The nine participants of the older children indicated that new mothers would need basic information about SCD that included information about its symptoms, special needs, what the child experiences during a crisis, and definitions/terminology associated with SCD. Additionally, the participants identified a need for information about what to do in a crisis situation, which was consistent with needs identified by the mother of the newly diagnosed infant. When asked about her informational needs as a new mother she stated,

I think the first thing that she would need to know is what is sickle cell disease; the basics. I think the book is very informative so that we can educate ourselves on exactly what it is and then maybe a crisis management plan...that if x, y, z

happens do this, if this happens, do that and I think that would be crucial for everyone, new parents as well as parents who are currently dealing with the disease.

Other major areas identified during this discussion were social support resources and resources that encouraging active learning. As one mother recalls,

My biggest thing was I needed somebody to tell me it was ok for me to ask questions and I wasn't asking the wrong questions and I didn't have to feel stupid or dumbfounded because I didn't know much about sickle cell disease. No matter what color I am, African American or not, I still wasn't educated [enough].

Another participant added, "... even a back-up, like, well you can call Helen. I mean she's not doctor Helen, but she's just Helen and that would be helpful."

5.2.2 What Additional Self-Care Management Resources Do Caregivers Need?

When asked about what additional information they needed, the caregivers requested information about their child's pain and how to management it. Specifically, the parents desired more information about pain management, pain plans, as well as pain medications, experimental drugs, and their known side effects, "instead of our actually asking if we can look into the book and say, you know...new medications that we give, instead of saying what's morphine, like you know, and how does that affect my child? How do y'all give it, you know, by weight and all that stuff?"

Additionally, the parents voiced a need for a list of available resources for individuals with sickle cell disease and their families, as well as a list of frequently asked questions. One father suggested, "A pamphlet of stuff of some type of giving resources available, like where to get educational resources or having...sometimes you might even need child care; whatever the case may be."

5.2.3 What Types of Self-Care Management Resources Do Children and Teens Need?

During the discussion, parents reported that they wanted information and resources for themselves that would help them aid their children in effectively coping with and managing their disease. This was a nice transition into this part of the discussion, in which the parents provided insights into the type(s) of resources they believed their children would want, need, and/or should have. One of the major themes that emerged during this discussion was a need for peer information and education to facilitate good decision making and independence. As one mother stated,

The problem that I'm starting to have now is that he's more independent, so I need for it [information] not come from mom. I need for it to come from other peers about some of the decisions that he's making, that I'm allowing him to make to a certain extent, to let him know, ok, now you know what the outcome of this is gonna be if it doesn't work out how you think it or you're over doing it. I think I probably helped create some of that because I didn't know what else to do. Instead of, maybe even chastising when I needed to or like, being firm, when I needed to, I didn't because who's to say how you're suppose to act when you have a sick child; you don't know what it's like until you go through it. So now, my baby is spoiled rotten and he's not even a baby. Now I want him, all of the sudden, to be this big boy and I never even let him be a big boy, he was always my baby.

In addition to providing peer information, the parents requested age-specific activities that would help educate the children and teens about sickle cell disease as well as provide an explanation for their special needs. One of the mother suggested, "...for certain ages maybe put it in, in an attractive way to make them want to read that, like a activity book, a coloring book, or something like that that shows why..." Another participant concurred, stating, "Yeah, yeah you know a break-down, like what she said...so give them an explanation as to why, you know, children want to know why..." One of the fathers added,

Something that we could put into our children's hands is an explanation for all that. For example, if they can't go swimming and you continue tell them all through their life they can't swim, they can't swim, well to put something in their hand...you can't go swimming because the cause the cold weather will contract your blood vessels and your blood, uh it sickle.

5.3 ASSESSING COMMUNICATION STRATEGIES

5.3.1 Who Should Provide Self-Care Management Resources and When?

When the caregivers were asked about who should provide the information and when information should be provided, they indicated that the obstetrician/gynecologist should be providing parents with initial information. One of the mothers stated,

I think information should be given out about sickle cell the moment that a woman becomes pregnant and they talk about prenatal care, as an African-American or someone from the Middle East or possibly even India, which the S-trait can come from all of those regions, as well as Africa. I believe that it should start right there in the OB-Gyny. If you're African American and you're pregnant maybe the question should be asked, "Do you carry a trait or do you have sickle cell disease? Does your partner have sickle cell disease?" It should start at the initial stages, so that way the information can hopefully be presented throughout her whole pregnancy.

Another parent commented,

Yeah you gotta be prepared when you make the decision and it should start at the ob-gyny. Once you go in to your ob-gyny they should know that you're a trait carrier even if you have a partner coming in with you or not, you should...I don't know. I guess somebody, maybe some people wanna take the test to see if the child will be born with it to make the best decision for you and your child.

In addition to the obstetrician/gynecologists' providing information about sickle cell disease, the parents suggested that providing information about SCD should be a community effort. As one mother responded, "I think that sometimes it takes a whole village to raise a child.

I think the communication and the education should be coming from all around, because Sicklers need help too.” The discussion continued as follows:

P2: Yeah they don't talk about sickle cell to much

P8: Thank you, you don't even hear it. It's like, it's like it doesn't exist but it does, it's real

P2: They don't talk about sickle cell and that hurts, that hurts me.

P3: It's starts in this room, right here, right today, that's what it's about.

P5: We, we don't talk about sickle cell.

The discussion became quite heated and emotional as it began to shift away from whom should provide caregivers with information to who should be providing information at the community level. During this side discussion, the parents began to explore the possibility that it was their responsibility to provide information about sickle cell disease to the community as well as to other parents and caregivers that constitutes a separate community among these caregivers. This discussion led to the conclusion that it is the responsibility of the caregivers themselves to provide information to others about SCD to effectively increase information at the community level.

Additionally, the parents suggested that information about SCD should be taught in high school. One parent said, “I think what they ought to do is start educating the kids in school. Have someone go in to the schools and educate the whole school, then you can eliminate every concern...” Another parent added,

...schools should start having all people come into the auditorium...principles, and different classes, the first grade...come in and they show like a play, either a live play or on a tv, where children are looking to [see] where it might affect them. Like, “Oh, my friend has that and now I know how to deal with that. I don't want to tease my friend like that anymore,” because they see this play or they see this little film that people got together and made and see how hurtful and touching it is to people.

5.3.2 How Should Self-Care Management Resources be Distributed?

When asked about how the information should be distributed, each parent expressed a preference for receiving the information either all at once or in stages. One mother argued, “I think that they should give it to you all at one time because if they give it to you in stages, there’s a chance that the stage that you’re child might be at, might be the stage that you didn’t get yet. So you’ll be sitting there and you’ll be confused, like if they never would’ve gave me the whole book, and I would’ve never known that my son was gonna go through that experience if I would’ve never of read the end of the book, cause it’s at the end.” On the other hand, another parent argued,

And me, I’m just the opposite. I think that we should go in stages and the reason why I say that is...upon getting tested and the test read that my child was going to have like this big percentage chance of being born with sickle cell...I would have hated and dreaded...for me to make a hasting, or a hasty, decision on not allowing my child to not be living because of what this book is telling me. All this stuff that my kid is going through because everything in that book does not mean that you’re kid is going to go through everything in that book, it’s just giving you things to look for. This could happen, this could happen, it does not mean that it is gonna happen, that would’ve scared me to death.

The mother refuted, ““But you gotta understand that even though they give it to you all at once and it’s gonna scare you, you’re already scared anyways because you’ve got a child that’s coming out with sickle cell. I was terrified.”

Despite having a preference for when the information should be distributed, the caregivers unanimously agreed that all available media should be used to provide information about SCD. There was some dispute over whether or not electronic media should be employed, as one participant addressed the fact that some caregivers may not have access to a computer. However, overall the caregivers indicated that all information should be provided in various media through different channels.

6.0 DISCUSSION

The results of the focus group will be discussed in this section. The limitations of this study will also be noted so that they may be considered when interpreting these findings.

6.1 FOCUS GROUP DISCUSSION

The specific aims of this study were to determine (1) where caregivers are receiving self-care management resources; (2) what types(s) of self-care management resources caregivers received; (3) what type(s) of self-care management resources caregivers and children with SCD still need in order to improve their quality of life; and (4) how and when self-care management resources about SCD should be provided to caregivers and who should provide this information, in order to determine what resources should be included or developed for the Children's Sickle Cell Foundation, Inc.'s Parent Advocacy Toolkits.

This study revealed that the only self-care management resources that the caregivers had received were SCD education materials and information was primarily gleaned from the "Sickle Cell Bible" provided by Children's Hospital Pittsburgh's Sickle Cell Clinic. The participants acknowledged that this resource provided them with general information about SCD; as one mother indicated,

The book explains what sickle cell disease was, where it comes from, it explains what the symptoms are, um...it explains side effects of certain medications that the child might be on, um what the temperature should, should not be and like, every other situation that could possibly go wrong with them, like, it explained everything in that book.

Despite receiving the “Sickle Cell Bible,” the caregivers reported that it was insufficient in providing them with enough good information in order to provide the best possible care for their child, especially during crisis situations, as it only provided “basic” information about SCD.

As a result, the caregivers admitted to seeking out supplemental information from alternative sources like the internet in order to fill their educational voids. This finding is consistent with a study conducted by Koontz et al. (2004), which found that caregivers of children with SCD who received information about their child’s illness through routine services displayed various knowledge deficits and tended to be misinformed, which could also be the result of acquiring supplemental information from alternative sources due to this lack of information. The sources of additional information identified during this focus group discussion varied from those found in the literature, which indicated that caregivers tended to rely on their informal social networks (family members and friends), community organizations, and various media sources (brochures, television, and magazines) for additional information. Although social networks were never specifically addressed during this discussion, caregivers originally from Africa reported receiving information from “back home,” where SCD is more prevalent.

Overall, the caregivers admitted that they felt that the “Sickle Cell Bible” and other identified resources did not provide them with enough good information in order to care for their child. These resources were found to have improved the caregiver’s knowledge of SCD, its pathophysiology and clinical manifestations, and their ability to recognize some signs and symptoms of crisis; however, this general information was not considered to be very helpful for

primary caregivers. Rather, it was suggested that this resource may be more helpful for secondary caregivers who may only need to know only the basics of SCD when providing short-term care and/or for new mothers as it would provide them with a brief overview of SCD.

Despite receiving inadequate self-care management resources, the primary caregivers attributed “asking questions” and “trial and error” to ultimately providing them with the best information. As one mother admitted,

I did get some information, basic information, bits and pieces, of sickle cell disease. Most of it didn't come from the Sickle Cell Society to be real honest with you. For me it was hands on pretty much and asking questions, always asking questions and probably workin' people's nerves but just wanting to know.

Another mother added, “I would honestly say, reading the book no, it doesn't, but with the hands on experience and you learning your child's body and knowing what to expect and what symptom that is what helps you better than anything as the years go on.” These methods of acquiring information were identified by primary caregivers to be more helpful and resulted in more specific information that filled in the gaps omitted in the “Sickle Cell Bible,” as primary caregivers need more than just basic information in order to provide the best possible care for their child, especially during a crisis situation.

Studies have found that passive learning, such as reading the “Sickle Cell Bible” does not adequately prepare caregivers for the responsibility of caring for a child with SCD. However, learning through “trial and error” and “asking questions” are forms of active learning, which can lead to an increase in self-efficacy. Studies have concluded that resources aimed at increasing self-efficacy have a profound effect on self-care management skills, as it empower parents to take control of and manage their child's condition and to advocate for the best possible care for their child, which results in improved education, practices, and health outcomes of both the child and their caregiver (Farrell, Wicks, & Martin, 2004; Kaslow & Brown, 1995; Houser et al.,

1992; Koontz et al., 2004). Unfortunately, the caregivers did not acknowledge receiving resources to increase self-efficacy from the clinic to help caregivers develop appropriate coping strategies, encourage them to be assertive and to ask questions, or provide alternative pain management techniques. Seeking out these resources were found to be innate behaviors among the caregivers; however, the caregivers did identify a need for these resources.

Caregivers with prior experience caring for a child with a chronic illness demonstrated an increased in self-efficacy and were more confident in their ability to care for and manage their child's disease. In fact, the caregivers acknowledged that they were more confident in their ability to provide care for their child versus the doctor's ability to care for the child. This finding is consistent with studies in the literature that indicate that physicians are not very well educated about SCD, its severity, treatment, and the prevention of pain (Yoon & Black, 2006; McGrath & Ruskin, 2007). As a result, resources created and disseminated by physicians, like the "Sickle Cell Bible," may indeed be lacking all of the necessary self-care management resources due to the physician's educational void. Hence, these findings are consistent with (Anie, 2008; Kaslow & Brown, 1995) that indicate that physicians may fail to provide these vital self-care management resources that enable caregivers to maintain control over and manage the day-to-day and life-long needs of SCD, which exacerbates poor health outcomes.

When asked about specific needs for self-care management, the caregivers requested "basic" educational resources about SCD that include information about signs and symptoms, special needs, and what the child experiences during a crisis. Also, the caregivers acknowledged a need for a list of available resources for individuals with SCD and/or chronic illnesses that provide support, guidance, and facilitate self-efficacy. Additionally, the caregivers requested that more educational information be made available within the community, as well as a need for

age-appropriate materials for children that provide information about their specific needs, as well as activities that allow children with SCD to interact with one another in order to facilitate peer education. These results are consistent with previous studies indicating that caregivers would like additional self-care management resources that “break down” information about SCD for themselves as well as their children (Bennett et al., 2006).

New themes emerged during this discussion that have not been reported in the literature: caregivers identified a need for additional educational resources that contain information about pain plans/management and pharmaceutical drugs and their side effects; “crisis management plan,” that contains information about what to do during crisis situations; and resources that encouraged caregivers to be more assertive and to ask questions, as one parent noted, “...new moms have to understand that they have to put their foot down...so that new moms don’t have to feel like they don’t have rights about their child, cause it is their child.” Furthermore, the caregivers requested that resources for children provide explanations for their special needs and help encourage independence and good decision-making.

Despite lacking self-care management resources, the caregivers did acknowledge their importance as well as the need for these resources and offered suggestions as to how and when this information should be disseminated and by whom, which has not been previously discussed in the literature. When asked about when the information should be distributed, there was no unanimous decision. Some caregivers expressed a preference for receiving the information all at once, so that they could be prepared and exhibit good decision-making in advance. Other caregivers preferred to receive information in stages as they admitted to being “terrified” and “overwhelmed” by all of the information about SCD. Despite these differences, the caregivers unanimously agreed that all available media should be employed to provide information about

SCD through various forms of media; however, there was some dispute over whether or not electronic media should be employed, as one participant addressed the fact that some caregivers may or may not have access to a computer. This finding is consistent with previous studies indicating that caregivers of children with SCD obtain information from different media (Treadwell, McClough, & Vichinsky, 2006).

Caregivers also indicated that the obstetrician/gynecologist should provide parents with initial information about sickle cell disease throughout their prenatal care. The participants felt that the obstetrician/gynecologists should be asking at-risk populations the questions, “Do you carry the trait or do you have sickle cell disease? Does your partner?” and providing them with information about SCD during prenatal care. In addition to the obstetrician/gynecologist providing information about SCD, the caregivers also requested that information about SCD be more readily available within the community at large as well as the sickle cell community. Caregivers indicated that they believed the community should be providing education and awareness about SCD, as a lack of information can exacerbate the poor health outcomes and psychological problems associated with SCD. Specifically, the caregivers felt that information should primarily be taught in the schools in order to reduce ignorance among peers and to raise awareness about SCD and trait status. This is consistent with findings in the literature that suggests that African-American caregivers of children with SCD prefer information from community organizations and their informal networks (Sterling, Peterson, & Weekes, 1997).

6.2 LIMITATIONS

Limitations of this study should be noted when interpreting these findings. A major limitation of this study is that only one focus group was conducted with caregivers of children with SCD as a result of the second component of the eligibility criteria which required that the child with SCD be enrolled in the Education Support Program and had participated in two or more of the program/events offered by CSCF during the past 18 months. This criterion was used to ensure that enough participants for a focus group, as participation among this population is low. Additionally, the focus group may have contained participants who are more actively involved in their child's care than those who were not eligible to participate in this study and therefore may have different self-care management information and needs than those who are not as actively involved. Thus, this discussion may not have captured all of the various needs of this community and these results may not be applicable to the larger population as a whole.

Another potential limitation of this study was the use of a parent to moderate the discussion. As indicated, the introductory portion of the focus group provoked an emotional response that resulted in a brief focus group discussion due to two hour time constraint. Memory is not instantaneous and may take time or prompting to retrieve past experiences in order to provide valuable insight. As a result, the participants may not have had enough time to fully reflect upon or thoroughly discuss their self-care management resource needs during the allotted time frame. Furthermore, the moderator displayed difficulty avoiding contributing her personal opinion and interjecting throughout the discussion. This may have persuaded the conversation in a different direction than if the moderator has not contributed her thoughts.

7.0 CONCLUSIONS & RECOMMENDATIONS

Overall, the findings from this study were consistent with those reported in the literature which suggests that physicians may fail to provide these vital self-care management resources that enable caregivers to maintain control over and manage the day-to-day and life-long needs of SCD (Anie, 2008; Kaslow & Brown, 1995; Koontz et al., 2004). Consequently, additional resources should be developed in order to address specific educational voids not addressed by routine service information, in order to empower parents to take control of and manage their child's condition and to advocate for the best possible care for their child (Farrell, Wicks, & Martin, 2004; Kaslow & Brown, 1995; Houser et al., 1992; Koontz et al., 2004).

In order to provide caregivers with the information that they need, the Parent Advocacy Toolkits should contain self-care management resources created by other caregivers and peers who have acquired accurate and valid information through trial and error experiences and asking questions. Caregiver resources should address assertiveness, coping behaviors, self-care abilities/actions, and self-efficacy as well as additional educational information about drug treatments and their side effects. Resources for children should be age-appropriate and provide information about independence, good decision making, as well as providing explanations about crises and special needs. Furthermore, social support resources should be provided to connect individuals with one another as well as community organizations that provide resources and services for children with chronic illnesses. These resources should be made readily available to

children and their caregivers through various media and disseminated to caregivers based on their individual preferences.

Further research should be conducted to develop and pretest these self-care management resources and to determine their impact on health outcomes. Additionally, future studies should be conducted to explore the caregiver's recommendations of preventative efforts and awareness information at the community level.

APPENDIX A

INSTITUTIONAL REVIEW BOARD (IRB) APPROVAL LETTER



University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
<http://www.irb.pitt.edu>

Memorandum

To: SAMANTHA POST
From: SUE BEERS PhD, Vice Chair
Date: 10/8/2008
IRB#: [PRO08090555](#)
Subject: Assessing Information Needs of Parents of Children with Sickle Cell Disease

The above-referenced project has been reviewed by the Institutional Review Board. Based on the information provided, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section 45 CFR 46.101(b)(2)

Please note the following information:

- If any modifications are made to this project, use the "**Send Comments to IRB Staff**" process from the project workspace to request a review to ensure it continues to meet the exempt category.
- Upon completion of your project, be sure to finalize the project by submitting a "**Study Completed**" report from the project workspace.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

APPENDIX B

PARTICIPANT RECRUITMENT MATERIALS

B.1 PARTICIPANT RECRUITMENT LETTER



Gove Business Center
226 Paul Street, Suite 102 • Pittsburgh, PA 15211
412-537-8973 • Fax 412-431-5214

Dear Parent,

As you know, the Children's Sickle Cell Foundation, Inc. (CSCF) is committed to providing social, educational, and economic support to children with sickle cell disease and their families. During our focus group this summer, many parents said that they would like more information about sickle cell disease so that they could better care for their child. As a result, CSCF is developing Parent Advocacy Toolkits with this information to give to parents and children who are in our programs. As a parent of a child with sickle cell disease, we would like to talk with you further about the type(s) of information that you want or need in these toolkits during lunch at Atria's Restaurant on Saturday, October 25th from 1-4p.m.

We will also use this time to conduct a focus group with the parents to determine what type(s) of information our families would like to have in the toolkits. Childcare will also be provided by the CSCF staff at Funfest, where the children will enjoy lunch and be able to bowl for the afternoon. Transportation will be provided to the venues and the bus will leave from Children's Hospital Pittsburgh at 12 (noon). We hope that you will join us and share your stories, while making new friends, forming support networks, and connecting with other parents like you.

Please contact Samantha Post at the Foundation Office (412-488-2723) for more information and to confirm your participation.

Thank you and Have a Blessed Day, Ever day!

Andrea Williams, BA
Executive Director,
Children's Sickle Cell Foundation, Inc.

Samantha Post, BS
Graduate Student of Public Health,
University of Pittsburgh
Student Intern,
Children's Sickle Cell Foundation, Inc

"Committed to Serving Children and Families"

B.2 TELEPHONE SCRIPT

Good Afternoon/ Evening Ms./Mrs./Mr. _____,

This is Samantha calling from the Children's Sickle Cell Foundation, Inc. and I am calling to invite you to our focus group Saturday October 25, 2008. I will be conducting research, as a University of Pittsburgh graduate student, to determine what types of information our families want and need in order to provide the best care for their child with sickle cell disease. This information will be obtained during a two-hour focus group conducted by Ms. Andrea Williams, the Executive Director of the Children's Sickle Cell Foundation. During the focus group, you will be asked to share your thoughts about the information you have received about sickle cell disease, as well as providing suggestions for improving this information so that parents can provide the best care for their child. Our discussion will be audio taped and I want to assure you that all of your responses will remain confidential and no identifying information will appear in my final report. These recordings will be kept in a locked file drawer at the Children's Sickle Cell Foundation, Inc. and destroyed upon completion of this study.

Your participation in this discussion is voluntary and you may withdraw from the study at any time. There are some possible risks associated with this study such as familiarity with other participants in the group which may cause discomfort in sharing your opinions and/or a breach of confidentiality. The benefit of participating in this study is that your thoughts and opinions will be used to develop materials based on these suggestions and you will meet other parents like you. The meals and activities provided for you and your child(ren) during the focus group are to thank you for your participation and sharing your thoughts. Are you still interested in sharing your thoughts with us during our focus group? Do you have any additional questions?

APPENDIX C

FOCUS GROUP MODERATOR'S GUIDE

Moderator's Guide: Assessing Information Needs of Parents of Children with Sickle Cell Disease Focus Group

A. Introduction

Hello, my name is Andrea Williams and I am the Executive Director of the Children's Sickle Cell Foundation, Inc. (CSCF). I will be conducting our discussion this afternoon. I would like to welcome everyone to our focus group discussion and thank you for taking the time to join us. With me today is Samantha Post, a graduate student from the University of Pittsburgh and CSCF Intern, who will be taking notes about the conversations that take place during our focus group.

You all have been invited because you share our commitment of providing support for your child, which has been demonstrated by your participation in our various programs. We admire the commitment you have made to your child and value your thoughts and opinions about how we can improve their quality of life. This research study was designed to understand what kind(s) of information parents of a child with sickle cell disease already have and what kind(s) of information parents still want and/or need in order to provide the best possible care for their child through our focus group discussion.

A focus group is a small group discussion that focuses on a particular topic in depth. We are here to listen to your ideas, thoughts, and opinions about this topic and I encourage you to share them with us today. In a focus group, there are no right or wrong answers, just different points of view. It is important that I hear what each of you has to say, because your thoughts may be similar to those of many other people who are not here with us today. Your ideas are extremely important to us, so please feel free to speak up even if you disagree with someone else. It is OK to disagree, because it is helpful to hear different points of view throughout the discussion.

Your participation in our discussion is strictly voluntary and I want to assure you that all of your comments will be kept confidential and will only be used for research purposes. There are some possible risks associated with this study such as familiarity with other participants in the group which may cause discomfort in sharing your opinions and/or a breach of confidentiality. The benefit of participating in this study is that your thoughts and opinions will be used to develop materials based on these suggestions and you can talk with other parents like you. Also, your participation will ensure that parents receive the information they need to provide the best care for their child.

We will be audio taping our discussion because everything you say is important to us and we want to make sure that we do not miss any comments. I want to reassure you, however, that all of your comments are confidential and will be used only for research purposes. Nothing you say will be connected with your name. Samantha will go through all of your comments and use them to prepare a report on our discussion and your names will not be included. Finally, if there are any questions you would prefer not answer, please feel free not to respond to them.

B. Assessing Routine Service Information

1. I would like to begin by talking with you about how you obtained your information about sickle cell disease. Where and when did you get your information?

Probe(s):

- Received information from CHP Sickle Cell Program
- Received information during well child visits

2. What type(s) of information did you obtain/receive?

Probe(s):

- Information about etiology
- Information about warning signs for adverse health concerns (i.e. crises and stroke)
- Information about special needs (i.e. temperature, hydration, and rest)
- Information about psychological problems
- Information about pain management

3. How helpful did you find the information that you obtained/received?

Probe(s):

- Did the information increase your knowledge/understanding of SCD and how to care for a child with this disease?

4. In general, do you feel that you have enough (good) information in order to provide the best possible care for your child?

C. Assessing Information Needs

5. Let's brainstorm for a few minutes about what type of information you think new parents would need in order to care for a child with sickle cell disease. [List suggested information on the easel]. Is there anything else that you feel should be included?
6. As a parent of a child with sickle cell disease, what type(s) of information do you feel that you may still need in order to provide the best care for your child? [List suggested information on the easel] Is there anything else that you feel should be included?
7. What kind of information would you like for your children to have about their illness so that they can properly take care of themselves in the future? [List information on the easel]

D. Assessing Communication Strategies

8. In an ideal world, what would be the best way to communicate information about sickle cell disease to parents, children, and teens?

Probes:

- Who should provide the information?
- When should the information be provided?
- Should information be given all at once or in stages?
- What channels should be used? (i.e. Booklets, brochures, website, CDs, etc.)

E. Close

We have come to the end of our discussion. On behalf of the Children's Sickle Cell Foundation, Inc. and the families that we serve, I would like to thank you for your participation this afternoon as your thoughts and opinions will be very valuable in creating and developing the Parent Advocacy Toolkits.

APPENDIX D:

FOCUS GROUP TRANSCRIPT

CAREGIVER FOCUS GROUP TRANSCRIPT

INTRODUCTION:

Moderator: Hello, my name is Andrea Williams and I am the Executive Director of the Children's Sickle Cell Foundation, Inc. (CSCF). I will be conducting our discussion this afternoon. I would like to welcome everyone to our focus group discussion and thank you for taking the time to join us. With me today is Samantha Post, a graduate student from the University of Pittsburgh and CSCF Intern, who will be taking notes about the conversations that take place during our focus group.

You all have been invited because you share our commitment of providing support for your child, which has been demonstrated by your participation in our various programs. We admire the commitment you have made to your child and value your thoughts and opinions about how we can improve their quality of life. This research study was designed to understand what kind(s) of information parents of a child with sickle cell disease already have and what kind(s) of information parents still want and/or need in order to provide the best possible care for their child through our focus group discussion.

A focus group is a small group discussion that focuses on a particular topic in depth. We are here to listen to your ideas, thoughts, and opinions about this topic and I encourage you to share them with us today. In a focus group, there are no right or wrong answers, just different points of view. It is important that I hear what each of you has to say, because your thoughts may be similar to those of many other people who are not here with us today. Your ideas are extremely important to us, so please feel free to speak up even if you disagree with someone else. It is OK to disagree, because it is helpful to hear different points of view throughout the discussion.

Your participation in our discussion is strictly voluntary and I want to assure you that all of your comments will be kept confidential and will only be used for research purposes. There are some possible risks associated with this study such as familiarity with other participants in the group which may cause discomfort in sharing your opinions and/or a breach of confidentiality. The benefit of participating in this study is that your thoughts and opinions will be used to develop materials based on these suggestions and you can talk with other parents like you. Also, your participation will ensure that parents receive the information they need to provide the best care for their child.

We will be audio taping our discussion because everything you say is important to us and we want to make sure that we do not miss any comments. I want to reassure you, however, that all of your comments are confidential and will be used only for research purposes. Nothing you say will be connected with your name. Samantha will go through all of your comments and use them to prepare a report on our discussion and your names will not be included. Finally, if there are any questions you would prefer not answer, please feel free not to respond to them.

DISCUSSION:

Question 1:

Moderator: Ok, assessing routine service information, this is Part B. I would like to begin by talking with you about how you obtained your information about sickle cell disease. Where and when did you get your information?

P1: I got my first information when I...um actually, got a book sent to me, they mailed it out from the sickle cell clinic and they sent the book to me and I actually really sat down and read through that whole book. The funniest part about the book was when they say, I can't ever say the word, but it's when the male goes through the hardening part.

Moderator: Priapism

P1: Yeah, I can't never say that word right, but that was the weirdest part to me cause I'm like, "What is that?" And my son has went through that and he's only 5, so that that's where I got most of my information and by looking it up on the internet.

P2: Uh huh, same here. I got my information like that too. I think it came, I don't know if yours came with it but mine I think came with like a little DVD that you watch.

P3: Periodically, uh...we would get our information from the internet. Just Google sickle cell and see what's on...uh, said there but... Primarily all our information comes from the clinic during our visits um over the years we participated in clinical studies, uh, you know Dr. Krish and crew you know, that's where we get most of our information.

P4: But our first information came from the sickle cell book.

P3: Oh yeah

P4: That big, thick book that they call the "sickle cell bible," which in the beginning I refused to read because I was in such denial.

P5: I got my information before my grandson...prior to sickle cell...before he was born when I was a teenager. Um, I was in certain programs and they discussed sickle cell and that's how the beginning of my information started. Also, I read the book that she has.

P6: I got mine back home from Nigeria where more people with sickle cell and some of my classmates that was suppose to graduate, but before I start school there were still classmates. So, I got information and idea of what sickle cell is from there... When I came back from there to Fatimah they called me from the hospital about 3 months and said she had sickle cell and, I don't believe, I said I don't believe she has sickle cell because of the way she was. I tell her she doesn't seem like a sickle cell child. So, they said if I don't believe I should learn through test. I went, they tested, uh, they said she has sickle cell. I hate to go to children's hospital because we live around West Penn, whenever she's sick with sickle cell crisis I will take her to this hospital and they ask me to Children's Hospital I wouldn't want to go. So they say that's where I

actually need to go, so most of the information or idea about sickle cell I got from home and sometimes from the clinic.

Moderator: Thank you, um, you wanna share something.

P7: Yeah, I got the information back in Togo when I was in high school. I studied science so I know about it but I don't know I'm gonna be in this position.

P8: I got my first information about sickle cell, like, in my second trimester of pregnancy. Um...I already knew that both my husband and myself were trait carriers and I know that I needed to get tested. You know, uh, I thought that was very important, like, always being told that if you have sickle cell trait and you have a mate with sickle cell trait, you know, but were just blessed and very fortunate that none of our other children had been born with the disease, you know, and then being that I had was pregnant with the multiple births they just really tested and tested you know so that was my first inkling.

Question 2:

Moderator: Ok, What types of information, um, did you receive in this bible or types of information were there? Like, how you got sickle cell disease? Or warning signs? Or special needs, um hydration, temperature, any psychological problems, or pain management ? Were there any information like that in there?

P5: That hydration thing I've just come to know that when she says... you know, always when there's something wrong you need a lot of water and that's a primary thing that you need but the way that's its stressed wasn't stressed to me so I'm fairly new at that. So knowing that, instead of juice it'd be water would be more important than the juice and, and...um, I noticed that my grandsons urine always turns orange so I always think that a little water would keep it from being orange.

Moderator: But thinking back more so on the very first information that you received when you were first diagnosed.

P1: When, um...The first information that I received when I was first diagnosed...well, I really didn't know nothing until they sent me the book. The book explains what sickle cell disease was, where it comes from, it explains what the symptoms are, um...it explains side effects of certain medications that the child might be on, um what the temperature should, should not be and like, every other situation that could possibly go wrong with them, like, it explained everything in that book. If you don't read that book you won't know what, what is going on, that's what I suspect.

Moderator: Ok

P4: And it also explains that its hereditary, it's not a contagious disease that you get from anybody else, you know from eating or drinking from behind anybody

P3: And it also told, well, we first learned, um, what causes it why the pain comes from the limited blood and the blood vessels and all that, but that's some of the original information we got

Moderator: ok, um...did you want...

P8: I just was going to say I can just remember being told, you know, about some of the warning signs about actually a crisis situation instead of basically...I did get some information, basic information, bits and pieces, of sickle cell disease. Most of it didn't come from, um, sickle cell society to be real honest with you, for me...um...it was just like hands on pretty much and asking questions, like always asking questions and probably workin' peoples nerves. But just wanting to know, you know? And uh...I found out about the hydration and also, you know...pshh... fever, hospital immediately no question. No Tylenol, no nothing straight in and also with the dactylitis with the infants, you know, and my son always, his hand, he always had a puff on his hands and on his feet, you know.

P1: I have one thing to say...um, pertaining to the fever situation. There's sometimes when my son has a slight fever, where it'll be like 99.8 or something like that, I won't rush him to the hospital. I'll give him some Tylenol, a warm bath, and make him lay down and he'll wake up the morning and no problems, no issues. So, I don't believe that you should have to rush him to the hospital every time, unless it's over a hundred...

Group: Right, uh-huh

P1: Because when it's like 99.8 or something like that sometimes they admit them at a hundred and I gave him some Tylenol, laid him down, wiped him down and he went to sleep, woke up the next morning and no problems.

Question 3:

Moderator: Well, I'd like to talk to you guys about that a little bit later but I need to...uh, get us back on this other thing. I definitely have some information for you on that. Uh, but, did...how helpful did you find the information that you obtained to be? How, how helpful was it? The information that you received whether it was through the clinic or through the internet or where ever you found it, how helpful was it in your um...?

P3: That's, that's a really hard question to answer...um...because, I mean like when, when they're in crisis and you take them to the hospital they're already in pain. And then they pump em' full of morphine and blood and all that kinds of stuff. They're still in pain and they're in worse shape because they're hot up off these drugs and out of it over, behind these drugs. I know that's very, that's what happens to us.

Moderator: Did it help you navigate through or, or am I asking the right question? Did it help you...um, better care for your child?

P1: I would honestly say... um, reading the book no, it doesn't, but with the hands on experience and you learning your child's body and knowing what to expect and what symptoms...that is what helps you better than anything as the years go on.

P4: Correct

P3: Trial and error

P2: Every child is different, like my son, he got sickle cell disease but he also got G6PD and G6PD is an iron deficiency. He can't eat certain foods and stuff like that, like fava beans, can't be around moth balls and that affects his...uh...his blood too with the...uh, the oxygen. So he has two things going on that I have to be...uh, you know, aware of. But as far as the book, it was only like sixty percent helpful but speaking with other people and, like she said getting to know your child, that makes it more helpful for you.

P5: And, and I'm on the other side because I don't have the book at home. So when, when my grandson gets left with me, the book would be helpful to me. Cause the things that I, I read in the book help me to understand what might be a crisis situation that seems real simple at that moment. See, when they would've taken the child to the hospital, I would be sitting there thinking, if I had more information then I would know if this is the time to go or do I wait a minute or do I try something else? So, the book would be helpful for me because I'm not in it every day. I'm just on the side sometimes and, and that's the hardest part for me because I think that if I make the mistake of not going to the hospital, I don't get sleep, I worry, if I can't get a hold of her...its, it's real hard. But if I had the book, then I could go look through to that part and that would help me to get through it easier.

Moderator: Ok, I need to ask a question, did everyone receive a book?

P8: I can't even remember

Group Discussion of mixed results that is unable to be made out. To summarize, "the book" is a thick, stapled together pamphlet of information

P8: You know, I don't think that we actually did receive the book, you know. My son was born, like I said, in 1996. We didn't get a book in 1996.

Moderator: We didn't get a book in 2000

Group Discussion of mixed results about who received a book that is unable to be made out. To summarize, not everyone received a book.

Question 4:

Moderator: Ok, I have another question for you guys...Um, in general, do you feel that you have enough *good* information in order to provide the best possible care for your child?

P1: NO

P2: I feel I do because...um, I, I have a child that has sickle cell and I had a child that had leukemia and leukemia is cancer of the blood, so they're both blood disorders. So, I'm a little bit more educate, ed, you know, on you know what's going on, but the things is the doctors and the nurses aren't. I'm tired, I'm tired of doing their job. I have to tell them da, da, da, da, da, da, you know what I mean? They should already be aware of it...aware of the disease more, and not just that, my child in particular. They should already have something in the computer about my child, not just how to manage his pain, but about him period.

Question 5:

Moderator: Ok...um, alright...Section Number C is Assessing Information Needs. Let's brainstorm for a few minutes about what types of information you think new parents would need in order to care for their child...with sickle cell disease.

P8: I think that kinda, some of the most, some helpful information...some helpful information for me is this as far as helping people, new families with sickle cell?

Moderator: Yes, the question is, uh..., "Let's brainstorm for a few minutes about what type of information you think new parents would need in order to care for a child with sickle cell disease."

P8: Um...temperature, temperature is a big one, um, like with the fever. Hydration is a huge one. Medication...is...

P3: Knowing when to go to the hospital.

P8: Exactly

P3: Temperature is a big thing. When it breaks that hundred you're outta there.

P1: To me I feel it's more of knowing what crisis your child is going through because I go to the hospital and they can't tell me what part is hurting. They can't tell me if it's his foot, his leg, his arm, his chest and that right there kills me the most because I don't know what's hurtin. My son will say my stomach, my legs hurt but it might just be he just got pneumonia in his chest, but every part of his body just starts hurtin.

Moderator: So the new mom, if you were going to see, tell a new mom...um, what type of information...uh... would that new mom need. What is the most important information that a new mom, newly diagnosed, ten days old...

P10: I think the first thing that she would need to know is what is sickle cell disease, the basics. I think the book is very informative so that we can educate ourselves on exactly what it is and then maybe a crisis management plan? Which is what, actually, my husband and I did with the daycare facility that our children...uh, go to. For our baby, we have a crisis management plan,

literally, that if x, y, z happens do this, if this happens, do that and I think that would be crucial for everyone; new parents as well as parents who are currently dealing with the disease.

P1: I think that a new mom should also learn her child because as my son, with my son, you could tell the difference between my son. He goes from, "Oh, hi mom! Yeah, yeah," jumpin all off the walls like a bouncing cat or something, then he goes from swoooosh (Indicating a dramatic decrease) and he's like, I call it a dead person. That's how you know when my son is sick, because when he's real sick he becomes a totally dead person when it's real bad.

P5: And you said a new mom, um...my grandson, you said ten days old, that's what stopped me. Cause um, the child's reflexes aren't as strong when he's going through that. Like my grandson started jaundicing, he was turning yellow, like the node of their eyes, the color of their eyes, that's really important when they're newborn, especially when you find out they have the trait. That their eyes was yellow cause they can't say anything, they'll cry or their body texture will turn yellow, because he was jaundicing, you know, and if you're not aware of it you're not gonna see it in that manner.

P8: But also if things like the parent...my biggest thing was...I needed somebody to tell me it was ok for me to ask questions and I wasn't asking the wrong questions and I didn't have to feel stupid or dumbfounded because I didn't know much about sickle cell disease. No matter what color I am, African American or not, I still wasn't educated upon...but I didn't need to much education cause it scared me, like just enough to get me through Point A to Point B

Moderator: Today

P8: Today, exactly, cause too much of that stuff is like whoow

P5: And then in the sickle, especially new moms, because that was her first child, new moms have to understand that they have to put their foot down. Like when they didn't have the cover on him, go in there and tell him to cover him up and to keep him warm, so that new moms don't have to feel like cause they're a new mom they don't have rights about their child, cause it is their child.

Moderator: Ok

P4: Well I think it's very important for a new mom when they know that they, when they get that test saying that they have, that their child has that sickle cell...it's when they're sick and they do have a fever, you get them to that hospital. You let them know as soon as you get through that front door you, you're child has sickle cell. The small, may not know what's going on but get some, they're suppose to take them immediately.

P5: Immediately!

P8: Also...I was just gonna say, they're um, they're um...their number, like their hemoglobin number, what do you call that? That like a....blood count? What is supposed to be...

Moderator: Baseline

P8: The baseline...you know those numbers or their, that child's numbers like that...

Moderator: The type of sickle cell

P1: The re-tick Number, hemoglobin

P5: The terminology...because, cause see she, she...you're saying these things and they're not, I'm getting them but some of them are going over my head, because the terminology is very important so that I can understand what you're saying. So that you're saying the words and you know exactly what your words are and what they mean.

P1: The re-tick number is the white blood count and you need to know that...

Moderator: Ok and we can talk about all those things, um...in, in... I'll explain all those to you.

P2: I was gonna say what probably could be helpful, is a lot of people don't read, they'll go home and just put that book to the side, you know, especially some young, some young moms. Just like, uh, when I got home, you know, with my son and, you know, I thought that, you know, I'm a new mom I'm just, you know, gonna do what I need to do and then I was called to bring him back back in. I think that new moms should be asked to go to a suspected group within two week of bringing their child home. That way at least we know that they're not, probably not reading but they gonna to come into this group and get more information, you know, from people like us. So maybe a group that they could be send to within two week, or maybe within a month, send them to a group.

P5: That was good and, and even a back up, like, well you can call Helen. I mean she's not doctor Helen, but she's just Helen and...you know, and even leave it to the parent to call that person. That would be helpful.

Question 6:

Moderator: Ok, let's go on to number six...as a parent of a child with sickle cell disease...can you guys hear me? As a parent of a child with sickle cell disease, what types information do you feel that you still need...may still need, in order to provide the best care for your child. What information do you think you still may need?

P8: Some information on, on his, uh, pain plan, uh, pain management

P1: I want some information on where the pain is starting

P2: Probably more information on the drugs that we give them, instead of our actually asking if we can look into the book and say, you know...

P3: Side effects and things like that

P2: New medications that we give, instead of saying what's morphine, like you know, and how does that affect my child? How do y'all give it, you know, by weight and all that stuff?

P3: Uh, a pamphlet of stuff of some type of giving, you know, resources available. To you know, like where to get educational resources or having...sometimes you might even need child care; whatever the case may be.

P4: Frequently asked questions

P8: And something for...like everything's sorta concentrated on the parents and these little children grow up and they're getting older, something for them to understand what their bodies are going through because it's actually happening to them.

Question 7:

Moderator: Good, good. Ok, we're almost finished. What kind of information would you like your children to have, so that they can properly take care of themselves in the future?

P8: I know my son...I guess he's just at the age now where, you know, he wants to play sport and we've let him but sometimes when it's hot outside you can't do twenty-five laps because the coach said that's what you gotta do for football. No, it is eighty-two degrees outside...uh huh. So the problem I'm starting to have now is that he's more independent. "Oh, mom I know I'm supposed to have my coat buttoned up, I'm alright ma." I need for it not come from mom, I need for it to come from...maybe peers...other peers, about some of the decisions that he's making, that I'm allowing him to make to a certain extent, to let him know, ok, now you know what the outcome of this is gonna be, you know, if it doesn't work out how you think it or you're over doing it.

Moderator: Would it be helpful to have a peer model or something to ask the older children

P8: Something...I don't know what to... I have no idea but I know he doesn't want to accept it from mom or dad. You know, it's like saying, you telling me that that stove is hot and I know that the stove is hot cause I gone done touched it before, but I'm a little older now and I'm gonna try to touch that stove again.

P3: The invincibility factor that teenagers have

Moderator: What would you like to put into your child's hands? What would you like to see...

P1: I would like my son to learn how to calm down when it is necessary cause there be times and moment when my son is like, he's real, real hyper but he knows that he needs to lay down. You could tell he's tired because you can see all in his eyes but he'll be like, "I'm not tired, I'm not sleep, I don't want to go lay down." He needs to learn that it's time to lay down, like there's sometimes he gets home, like he'll wake up at eight o'clock in the morning, he'll try to stay up until, like, nine o'clock at night and I'm like, "You gotta take a nap in between because you have

to have the rest that you need,” because otherwise he’ll be tired, goofy, real, get real silly, and he’ll be real hyper.

P3: That, that’s really interesting. Um, something that we could put into our children’s hands is an explanation for all that. For example, if, like, they can’t go swimming and you continue tell them all through their life they can’t swim, they can’t swim, well to put something in their hand...you can’t go swimming because the cause, the cold weather will contract your blood vessels and your blood, uh it sickle.

Moderator: Or how about that you can go swimming if you...not jump in cold water

P3: Yeah, yeah you know a break-down, like what she said, “That he has to rest,” but why does the child have to rest? You know, so give them an explanation as to why, you know, children want to know why...

Moderator: We all still want to know why...don’t we all want to know why?

P2: And, and for certain ages maybe put it in, in an attractive way to make them want to read that, like a activity book, a coloring book, or something like that that shows why...

P10: Age-specific

P2: Yeah

P3: Age-specific

P2: And for older children, like all the information in the front, but like a diary and in the back they can write like, “I experienced that on page two.”

Group: That is a good idea

Moderator: Maybe do it electronically?

P3: That would be even better

P5: Even if you don’t have a computer, being realistically now, when...c’mon, I’m a diabetic and I don’t like shooting myself every day. I’m a little kid and you’re taking me to the hospital to stick me with needles all the time. Something in there that let’s understand and know that it’s ok not want this done too and not to want to go lay down and wanna to continue to play, cause I know that we push it as adults and I don’t see why we don’t expect the kids to wanna to push it. It bothers us more that they’re still running than it bothers them. My grandson falls on purpose. He knows his leg might hurt tomorrow, but when you put the thought pattern in his mind he still plays but he’ll play to an extent then. But, you know, we all be like, “No, I ain’t taking that now.”

Question 7:

Moderator: Ok now, let's go on to something different. Assessing Communication Strategies is Section D. In an ideal world, what would be the best way to communicate information about sickle cell disease to parents, children, and teens. Um...who should provide the information? How, when should the information be provided? Should we give the information all at once or in pieces? What channels should be used such a booklets, pamphlets, etc.?

P10: I think information should be given out about sickle cell the moment that, uh...a woman becomes pregnant and they talk about, uh...um...prenatal care, as, as an African-American or someone from the Middle East or possibly even India, which the S-trait can come from all of those regions, as well as Africa. I believe that it, um, should start right there in the OB-GYN. If you're African American and you're pregnant maybe the question should be asked, "Do you carry a trait or do you have sickle cell disease? Does your partner have sickle cell disease?" It should start at the initial stages, so that way the information can hopefully be presented throughout her whole pregnancy.

[Pause.] Moderator: Anybody else?

P5: What about before? In high-schools in the health classes?

P8: I think that sometimes it takes a whole village to raise a child. I think the communication and the education should be coming from all around, because, I don't... one of my biggest things, and I know this is horrible for me to say this, but when I go to the bank, I see all these things about Jerry's kids and this organization and that organization, but guess what...and it hurts me when I see that, not that I'm not thinking that these other children and families need the help, I understand that, but sicklers need help too. Where are we getting...

P2: Yeah they don't talk about sickle cell to much

P8: Thank you, you don't even hear it. It's like, it's like it doesn't exist but it does, it's real

P2: They don't talk about sickle cell and that hurts, that hurts me.

P3: It's starts in this room, right here, right today, that's what it's about.

P5: We, we don't talk about sickle cell

P8: I don't see it on t.v. or being flashed on the big billboards or...um..ad pamphlets being passed out in the neighborhood...um...

P3: It's because those families, they come together and they, and they push that effort. And, and, you know, if it's not pushed it's not going to happen.

P8: Well I think it should be pushed

P3: And that's what's happening in this room

Moderator: Ok, I agree, I think it's great but I need to get a couple of these questions answered and then we can have our discussion....Um, about how...the information is...when you have a child with sickle cell disease, how, who do you think should share the information with you? Once you have a child with sickle cell disease, you're diagnosed and in the hospital, where do you think the information should come from? You know, do you want...I heard a couple people earlier, you know, about being overwhelmed, should it all...should they give it to you in a bible all at once or should they give it to you in stages? Um, I mean what do you think is the best way and by which channels?

P1: I think that they should give it to you all at one time because if they give it to you in stages, there's a chance that the stage that you're child might be at, might be the stage that you didn't get yet. So you'll be sitting there and you'll be confused, like if they never would've gave me the whole book, and I would've never known that my son was gonna go through that experience if I would've never of read the end of the book, cause it's at the end.

P8: And me, I'm just the opposite. I think that we should go in stages and the reason why I say that is...upon getting tested and the test read that my child was going to have like this big percentage chance of being born with sickle cell...I would have hated and dreaded...for me to make a hasting, or a hasty, decision on not allowing my child to not be living because of what this book is telling me. All this stuff that my kid is going through because everything in that book does not mean that you're kid is going to go through everything in that book, it's just giving you things to look for. This could happen, this could happen, it does not mean that it is gonna happen, that would've scared me to death.

P2: Still be ready, gotta be ready for that

P8: Yeah you gotta be prepared when you make the decision and it should start at the ob-gyn. Once you, you know, when you go in your ob-gyn should know that you're a trait carrier even if you have a partner coming in with you or not, you should....I don't know. I guess somebody, maybe some people wanna take the test to see if the child will be born with it to make the best decision for you and your child.

P1: But you gotta understand that even though they give it to you all at once and it's gonna scare you, you're already scared anyways because you've got a child that's coming out with sickle cell. I was terrified.

P8: But I wasn't, I wasn't

P1: I was

P8: I wasn't

P1: I was, I was a new mom, first kid.

Moderator: Ok, ok, well um...what do you think is the best channel to disseminate information? Um, you know, going to clinic visits, having booklets, brochures, websites, cds?

Group: All of the above

P2: I wanna take that back because I think that DVD I did get was on leukemia, I don't think that it was on sickle cell. So, maybe, you know, we could come up with a DVD.

P3: They did have one, remember at Christmas...it was blue and it had the sickle cell on it

Moderator: Ok, well, thank you. Anyone have any...

P5: I'm a new parent and I don't have a computer

P6: Inform the teenage girls about the sickle cell so that they may be tested before they get married

P5: And if you don't have a computer...pamphlets always work no matter where I go. They make you aware. If you're a young woman out here and, you're, you're, um, you're sexually active, you're not asking somebody are they carrying the sickle cell trait. Something that says, learn to ask the question. Do you carry the trait? Cause then the possibility of creating children with the disease may become less, you know, but that becomes awareness for our young men and our young women. Is just do you carry the trait? And it would help a lot of things to be easier.

Moderator: Ok, well...

P9: I think what they ought to do too, is um, start educating the kids in school. You know, have someone go in to the schools...

P8: Uh huh,say it and speak

P9: And educate them because, um...also Denzelle had a problem where the kids found out, just you know, like with being sick. They would make cards, like, for him and send them to him at the hospital, but at the same time, the kids were ignorant towards what he had. And they were saying that, that um, if he touch em' they'd get sickle cell...

P8: And these are seventh graders, these are not like, they you know...

P9: And I talked to Tia before cause she had started talking about trying to make some pamphlets specifically for the school to educate the teachers and the faculty, because some of the teachers was even was asking me, "What is sickle cell?" You know, and I mean like, I told them what it was but still they wasn't telling the students. So you know, like, I told them that I was gonna try to get some kinda literature so that they might get, educate the students, and you know, which Dr. Krish, cause I had talked to him about it because Denzelle was really hurt about it.

P8: And sometimes now when he goes to the hospital, he will tell the doctors, "Oh, you can take me off this PCA pump, I don't need it anymore, I'm fine." And my baby is still sick because he

just wants to come out of that hospital and he has these doctors like eating out of his hands. “Oh, um, well, if he knows his body, we’re just gonna take him home.” And he still come home, comes home in pain and he’s still home for another week after he’s already been released and missed maybe a week in the hospital already...you know, just because... he doesn’t want to deal with it at times.

P1: About the school, my biggest fear, because my son just started school, he’s in kindergarten, my biggest fear was sendin him to school and the teachers did not know about his sickle cell. So, what I did in order to keep my son safe and to make sure that his teacher knew about his disease, just a little bit. I went on the internet and I got her the symptoms, the signs, I got her, um...what he needs to, like have, be hydrated, stuff like that and I gave her the information. So, she would know a little bit more and I gave the nurses office some, so neither one of the would be confused if he goes through a pain crisis, you call me ASAP, you know what I’m saying. And that’s what they been doing and his teacher works with him, I love it, his teacher’s a very nice lady, she works with him and she asks him, like if he forgot his water bottle, “Where’s your water bottle at?” You know, my son come home, “Mom, I forgot my water bottle,” and stuff like that. So, she’s works with me as well as I’m working with her in order to learn it.

P9: But you know what, that works, but every, every year, every year, like when they pass and go to the next grade, you gotta do it all over...

P8: They were giving packets, the social workers were handing out packets

P9: But if they work at the school, somebody go in and educate the whole school. Then you can eliminate, you know, every concern...

P2: I’m not gonna talk to long. I was just gonna say, yeah, um, I see what you was sayin’ , like they go to another year, you know, a different school. Like, um, schools should start having like, to where like people, all people come into the auditorium...principles, and different classes, the first grade...they come in and they show...for it not to be boring, like some students would fall asleep with all literature, oh like literature, that’s boring, oh that don’t interest me. Have it like a play, like a play, either a live play or on a tv, to where children are looking like, to where like it might affect them, like, “Oh, my friend has that and now I know how to deal with that. I don’t want to tease my friend like that anymore,” because they see this play or they see this little film that people, you know, got together and made and see how hurtful and touching it is to be...to people.

P9: That’s how it is because my son gets into a lot of fights. Because, you know, like, they talk about him and they say he’s weak and, you know, I mean it’s still just crazy...

P8: Well you know, I think I, uh, I, uh, probably helped create some of that. I always kept him here...because I didn’t know what else to do and instead of, maybe even chastising when I needed to or like, being firm, when I needed to, I didn’t. You know because, who’s to say how you’re suppose to act when you have a sick child, you don’t know what it’s like until you go through it. So now, my baby is like spoiled rotten and he’s not even a baby, now I want him, all of the sudden, to be this big boy and I never even let him be a big boy. He was always my baby.

P5: When y'all do the sheltering, when they go out for real, like when my grandson goes out, like when you go to school, it doesn't matter what's wrong with you, you're gonna catch it. So they have to understand...ok, I'll be quiet.

CONCLUSION:

Moderator: We have come to the end of our discussion. On behalf of the Children's Sickle Cell Foundation, Inc. and the families that we serve, I would like to thank you for your participation this afternoon as your thoughts and opinions will be very valuable in creating and developing the Parent Advocacy Toolkits.

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