

**SICKLE CELL PATIENT AND PARENT SATISFACTION WITH PAIN
MANAGEMENT IN THE EMERGENCY DEPARTMENT**

by

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Sickle cell disease (SCD) is associated with significant morbidity, mortality and impaired quality of life. Vaso-occlusive pain crises are the hallmark of sickle cell disease and require frequent visits to the emergency room and admissions to the hospital. Even though national guidelines are available that address the ethical issues of pain management, patients with SCD often receive suboptimal pain control, especially during acute painful episodes. This project planned to determine some methods of improving patient care and satisfaction of pain management in hopes of being able to translate these methods to other health care systems.

At the Children's Hospital of Pittsburgh (CHP) individualized pain plans, which include lists of each patient's most recent pain medications, have been in place since 2002. Retrospective data was analyzed to determine whether admission rates have decreased since this time due to improved care and treatment of patients with SCD. Additionally, patient and parent satisfaction with current pain management was evaluated by the use of surveys, with questions regarding overall perceptions of treatment and care. We had also proposed to implement a quality improvement program in the ED to further improve care of patients with sickle cell disease presenting with vaso-occlusive pain crises and then reassess patient and parent satisfaction. However, time restraints did not allow a quality improvement program to be implemented at this time.

This study found that admission rates since 2002 had decreased at CHP, since the time that individualized pain plans were designed and put into practice. Baseline measurements of patient and parent satisfaction found that, overall, participants were satisfied with the care and treatment of pain they received in the ED. Future studies should involve developing further methods of improving patient satisfaction with pain management; a possible avenue to pursue may be working on decreasing wait times in the ED.

The public health significance of this research is that increasing satisfaction by improved care, treatment, and pain management may lead to improved quality of life for patients with SCD; additionally, similar steps to be taken in other hospitals to increase the level of pain management that sickle cell patients receive.

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PREFACE

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1.0 INTRODUCTION

It has been estimated that approximately 70,000 Americans have sickle cell disease (Givens et al., 2007). Sickle cell disease (SCD) is a hemolytic anemia associated with significant morbidity, mortality and impaired quality of life. In patients with SCD, polymerization of red blood cells results in a rigid, sickle-shaped cell that can cause various problems throughout the body. Vaso-occlusive pain crises are the hallmark of sickle cell disease and require frequent visits to the emergency room and admissions to the hospital. Studies have found that prevention of prolonged pain crises may help to reduce long-term health consequences (Jacob & Mueller, 2008). Treatment that is individualized for each patient, as well as increased physician knowledge regarding all aspects of SCD, has been found to lead to more effective pain management for patients with SCD (Ballas, 2005). Despite the availability of national guidelines that address the ethical issues of pain management (Joint Commission for the Accreditation of Healthcare Organizations (JCAHO) and the American Pain Society), patients with SCD often receive suboptimal pain control, especially during acute painful episodes (Jacob et al., 2003).

A large number of physicians and health care professionals are not familiar with SCD and the characteristic pain episodes. This may lead to sickle cell patients being perceived as drug seekers or abusers by health care professionals not familiar to their needs for pain relief (Aisiku et al., 2007). Limited knowledge or experience with SCD may lead to mistrust of the patient by the physician which may actually lead to over-control of pain management. In turn, this can

result in the patient having decreased knowledge and independence, and increased anxiety, in regards to the treatment of his/her pain (Maxwell et al., 1999). Overall, this may lead to suboptimal care of these patients and decreased patient satisfaction with pain management, especially in the emergency department. If ED staff is trained specifically about sickle cell disease, pain management and treatment may be improved in patients leading to increased patient satisfaction.

At the Children's Hospital of Pittsburgh of UPMC, individualized pain plans for each sickle cell patient were implemented in the ED from 2002 to 2003. These plans include medication plans for the patient when seen in the ED, if they are admitted, and their home medication list. Whenever the patient is seen and changes to their dose are made, this information is updated, so that the ED always has the most current pain management information for each patient. Analysis of retrospective data from 2002 to present will be used to determine how these individualized pain plans have affected variables of patient care, such as rates of admissions and readmissions. These numbers will be compared to data from other hospitals across the country with similar pediatric sickle cell programs; this data was collected through the Pediatric Health Information System (PHIS).

This study will gauge patient and parent satisfaction with pain management in the ED following the implementation of individualized pain management and more knowledgeable staff. Patient and parent satisfaction will be measured by use of survey regarding overall care, treatment, and pain management. This survey will be administered to patients (ages 5-21) and their parents who were seen at a hospital emergency department upon completion of their care. It is believed that patient and parent satisfaction will be high due to individualized pain plans and increased knowledge and understanding of SCD.

The public health significance of this research is that by determining sickle cell patient and parent satisfaction after the implementation of personalized pain plans in the emergency department similar steps may be taken in other hospitals or in ambulatory care to increase the level of pain management that sickle cell patients receive. Additionally, increasing satisfaction by improved care, treatment, and pain management may lead to improved quality of life for patients with SCD.

2.0 SPECIFIC AIMS

2.1 SPECIFIC AIM I

Evaluate and compare retrospective data about sickle cell patients from Children's Hospital of Pittsburgh and Child Health Corporation of America (CHCA) hospitals.

Rationale: In the past few years, advances have been made in the care and treatment of patients with sickle cell disease. Treatment of patients has improved as understanding of sickle cell disease has increased. In patients with sickle cell disease, when pain is managed early and aggressively outcomes include better control of pain, reduced suffering, and decreased hospitalizations. Previous studies have found that improved treatment of pain results in decreased hospital admissions. Thus, rates of hospital admissions will be used as a surrogate marker to measure the quality of pain management. Retrospective data from CHP and various hospitals with similar pediatric sickle cell populations and programs will be evaluated from 2002 to the present.

Hypothesis: Individualized pain management plans implemented at CHP from 2002-2003 have improved the quality of pain management for patients with SCD by reducing rates of admissions.

2.2 SPECIFIC AIM II

Evaluate the current levels of patient and parent satisfaction with vaso-occlusive pain crisis management in the Emergency Department.

Rationale: Measuring current satisfaction levels will help determine a baseline level of patient and parent satisfaction.

Hypothesis: Improved quality of care for patients with SCD and their parents will lead to high levels of satisfaction with pain management, care, and treatment because pain levels are quickly and effectively reduced.

3.0 BACKGROUND AND SIGNIFICANCE

3.1 SICKLE CELL DISEASE

3.1.1 Molecular genetics of sickle cell disease

Sickle cell disease (SCD) is any inherited condition that causes a change in the structure or quantity of the hemoglobin molecule. Hemoglobin is a tetramer molecule comprised of two α -globin subunits and two β -globin subunits. Mutations in the *HBB* gene can cause abnormal structure or folding of the β -globin subunit, or β -chain. In classic SCD, a point mutation at the second nucleotide of the sixth codon of the β -chain will substitute a glutamic acid with valine. The abnormal structural variant of hemoglobin that is produced by this mutation is referred to as hemoglobin S (HbS). If an individual is homozygous for this point mutation, they have sickle cell anemia (HbSS). In compound heterozygotes, other mutations can occur in the β -globin genes that will cause an individual to be affected with SCD. Compound heterozygotes with hemoglobin S and hemoglobin C or β -thalassemia will also have SCD (HbS β^+ and HbS β^0) (Wilson et al., 2003). While there is a lot of variability in how an individual will present with SCD, generally those with HbSS or HbS β^0 -thalassemia will be more severe (Wilson et al., 2003). Sickle cell disease is inherited in an autosomal recessive manner.

3.1.2 Incidence of Sickle Cell Disease

It has been estimated that approximately 70,000 Americans have sickle cell disease (SCD) (Givens et al., 2007). This disease most frequently affects individuals of African and Mediterranean descent; however, it can also affect individuals of Middle Eastern, Arabian, Indian, Caribbean, and South and Central American descent (Wethers, 2000a; Wilson et al., 2003). In African-Americans, the prevalence of sickle cell trait is about 8-10%; about 2000 babies with sickle cell disease are born each year in the United States. This means that about one in every 250-600 African-Americans born in the United States has sickle cell disease (Shafer et al., 1996).

A higher incidence of the sickle cell gene has been found in individuals with descent from regions where malaria is common (figures 1 and 2). This is thought to be due to a heterozygote advantage, where people with sickle cell trait have an increased resistance to fatal malaria (Aidoo et al., 2002).

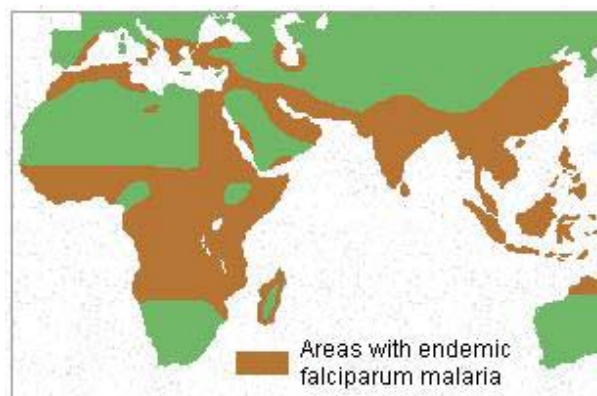


Figure 1: Areas with malaria

http://anthro.palomar.edu/synthetic/synth_4.htm

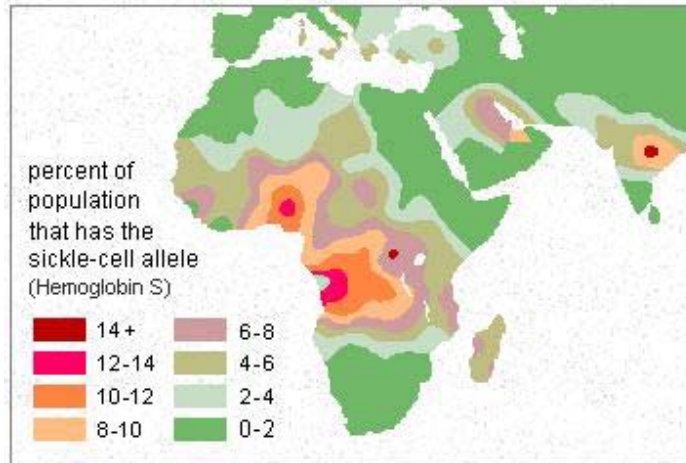


Figure 2: Areas with increased incidence of sickle cell trait

http://anthro.palomar.edu/synthetic/synth_4.htm

3.1.3 Natural History and Clinical Features of Sickle Cell Disease

In the human body, the function of hemoglobin is to transport molecules of oxygen from the lungs to the rest of the body. This function is hindered in individuals with SCD due to hemolysis and episodic vascular occlusion. Vaso-occlusion is the cause of the acute pain crises characteristic of SCD; it is caused by the polymerization, and subsequent aggregation, of the HbS molecules during deoxygenation. During this polymerization, red blood cells become sickle shaped, rigid, and less flexible. The damaged red blood cells, endothelium, and platelets increase the expression of adhesion molecules and may play a role in the initiation of vaso-occlusion. Vaso-occlusion can cause tissue ischemia which may result in acute and chronic organ damage or dysfunction. Hemolysis may reduce red blood cell survival from about 120 days to 20 days resulting in chronic anemia, jaundice, predisposition to aplastic crisis, and delayed growth and development (Wilson et al., 2003).

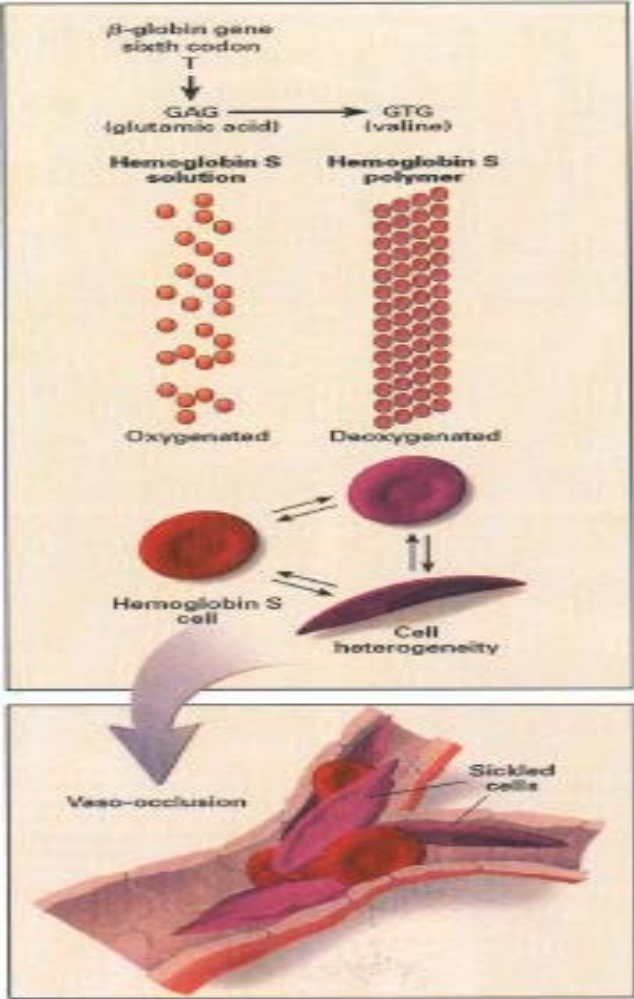


Figure 3: Process of vaso-occlusion

(Stuart & Nagel, 2004)

Often the first clinical manifestation of SCD is dactylitis, or hand-foot syndrome, seen in children under the age of three. This is a painful swelling of the hands and feet due to vaso-occlusion and may be a predictor of a more severe course of disease in a child. Vascular occlusion may occur anywhere in the body and therefore pain may be felt anywhere in the body; however, the most common areas where pain is experienced are the chest, back, abdomen, and limbs (Stuart & Nagel, 2004). Vascular occlusion can lead to tissue infarction, and possibly, a state of inflammation (suggested by in vivo studies of transgenic mice) that leads to the sensation of pain. Currently, the exact pathophysiologic sequence of events that leads to the perception of pain is unknown, but is believed to be complex, hence the considerable variability of pain experiences in this disease. Pain may be acute or chronic, unilateral or bilateral, visceral or somatic, localized or diffuse, and mild, moderate, or severe (Ballas, 2005). Caregivers should learn how to recognize and manage a pain crisis. In the case of mild to moderate pain, oral analgesics can frequently be used. If pain is not alleviated by this method, patients should be triaged and given IV narcotics if necessary (Wilson et al., 2003).

Children with SCD should be started on prophylactic penicillin by two months of age due to their increased risk for infections (Wethers, 2000a; Wilson et al., 2003). The development of splenic dysfunction at a young age increases the risk for children to experience infections from encapsulated bacteria, specifically *Streptococcus pneumoniae*, leading to sepsis. Penicillin should be given daily until at least the age of five. If the child has a history of pneumococcal infection, penicillin should be continued throughout his/her life (Wilson et al., 2003). Along with prophylactic antibiotics, children should receive all routine immunizations, as well as the pneumococcal-conjugated vaccine (PCV 7, Prevnar) and the pneumococcal polysaccharide vaccine (PPV23), the yearly influenza vaccine, and a semi-yearly meningococcal vaccine

(Wethers, 2000a; Wilson et al., 2003). If a child with SCD develops a fever over 38.5° Celsius or other signs of infection, he/she should be evaluated immediately because of the risk for sepsis due to splenic dysfunction. Evaluation should include a complete blood count and culture, a chest x-ray, and a physical exam. IV antibiotics should be started as soon as possible, as well (Wilson et al., 2003).

Besides pain crisis and infection, acute chest syndrome (ACS) is another common cause of hospital admission in patients with SCD. ACS is characterized by identifying new pulmonary infiltrate on a chest radiograph as well as the presence of other symptoms such as fever, cough, chest pain, shortness of breath, and wheezing. ACS may develop after an episode of vaso-occlusive pain or in conjunction with an acute infection (most often a pulmonary infection, infarct, or fat embolism) (Wethers, 2000b; Wilson et al, 2003). Treatment of ACS should be aggressive as pulmonary failure and death may occur. Treatment involves the use of oxygen, analgesics, antibiotics, and exchange transfusion while being closely observed in a hospital (Wilson et al., 2003).

The risk for stroke in patients with SCD is significant and occurs due to the polymerization and accumulation of HbS in the vasculature of the brain. The incidence of stroke is highest between ages 4-6; about 10% of patients with SCD have strokes (Wethers, 2000b). Children should be evaluated if they have any neurological symptoms other than a headache, a stroke may present as a severe headache, stupor, hemiparesis, dysphasia, cranial nerve palsy, or coma. Evaluations for stroke should include magnetic resonance imaging (MRI) or computed tomography (CT) without contrast, as well as a complete blood count (Wilson et al, 2003). Transcranial Doppler (TCD) ultrasonography may be done annually for HbSS patients beginning at two years of age. Blood flow velocity over 200 cm per second on TCD indicates an increased

risk for stroke (Wong & Powars, 2005). Patients who have had a stroke or are at risk based on TCD should undergo routine exchange transfusion (Wilson et al, 2003).

Pulmonary hypertension is one of the most serious and frequent complications in individuals with SCD. It is approximated that about 32% of adults with SCD will develop pulmonary hypertension (Castro & Gladwin, 2005). The pathophysiology of pulmonary hypertension is still unknown, although it is most likely multifactorial. The polymerization of HbS leads to fragility of red blood cells and their subsequent breakdown, or hemolysis. Hemolysis interferes with how nitric oxide is synthesized and utilized, and thus produces dysfunction in vasoconstriction. Screening for pulmonary hypertension is done by transthoracic Doppler echocardiogram and should be performed in all adults with SCD. If left untreated, the median survival time for individuals with pulmonary hypertension is 2.8 years (Castro & Gladwin, 2005).

Splenic sequestration is a complication of SCD recognized by an enlarging spleen, a decrease in hemoglobin levels, and a rise in reticulocyte levels. This typically occurs before the age of five and is caused by increased infections and immune dysfunction. Treatment for splenic sequestration is red blood cell transfusion. Prior to age two, chronic transfusion can be performed in children with severe or recurrent splenic sequestration; splenectomy should be considered for patients over two years of age if hypersplenism is chronic (Stuart & Nagel, 2004; Wethers, 2000b; Wilson et al., 2003).

Aplastic crisis is another complication of SCD where there is a temporary cessation of the production of red blood cells; this can lead to severe anemia. Aplastic crisis is typically triggered by an infection; most cases are caused by the human parvovirus B19. Many patients will recover

spontaneously, but red blood cell transfusions may be required if there is no evidence of recovery (Stuart & Nagel, 2004; Wethers, 2000b; Wilson et al., 2003).

Priapism is a painful, prolonged, and unwanted erection that is a common complication of SCD in males with almost 90% experiencing priapism by age 20. When it lasts less than 3 hours and resolved spontaneously, it is classified as a stuttering form. If it lasts over three hours, it is classified as a severe form and requires medical attention due to increased risks for fibrosis and impotence. Treatment of priapism should include IV hydration, analgesics, and exchange transfusion or penile aspiration of blood in the case of persistent or recurrent priapism (Stuart & Nagel, 2004; Wilson et al., 2003).

There are other health complications in patients with SCD that may be a result of chronic hemolysis. Gallstones may be caused by chronic hemolysis, with about 30% of patients with SCD developing them by age 18. These can be treated by cholecystectomy (Wethers, 2000b; Wilson et al., 2003). Liver dysfunction may occur due to vascular occlusion or chronic hepatitis and can be treated by exchange transfusion (Ballas, 2005).

In patients with SCD, there can be many structural and functional abnormalities of the kidneys. The kidney is especially sensitive to vaso-occlusion due to deoxygenation since the environment in the kidney is characterized by acidosis, hypertonicity, and hypoxia. All of these factors are involved in promoting HbS polymerization and may cause dehydration, which also leads to HbS polymerization. Problems with the kidneys in SCD patients may result in proteinuria and hematuria, which can be life threatening (Ataga & Orringer, 2000; Wethers, 2000b).

Leg ulcers can also occur in patients with SCD. The exact etiology of the leg ulcers is unclear; however, they occur in about 10-20% of patients, often between the ages of 10-25.

There is a higher likelihood of leg ulcers in males, as well (Serjeant et al., 2005). Treatment includes using wet and dry dressings soaked in saline and many ulcers heal within a few months; if the ulcers persist beyond six months, skin grafting or blood transfusion may be required. Pressure stockings may help to prevent the formation of leg ulcers since they may recur following minimal trauma (Ballas, 2005).

In addition to the physical manifestations of SCD, there are also psychological factors to consider. Individuals with SCD experience chronic pain, which is defined as pain that persists for three months or more. A key feature of chronic pain is that it provides no biologic function. Acute pain is useful to alert the body to a noxious event and to stimulate the fight or flight response to stimuli. Alternatively, chronic pain has no purpose and evokes no response in the body. Emotional distress and behavioral dysfunction may result from chronic pain syndromes (Ballas, 2005). Other psychosocial factors that should be considered as the child gets older are their feelings about their mental and physical changes during growth and the development of their peer relationships. Children with SCD typically lag behind growth and development curves by up to two years. They should be reassured that they will catch-up and will be an average size as an adult. Children have to learn how to manage unpredictable absences from school or social gatherings due to illness. They also need to understand the limitations to their physical activity and learn to avoid dehydration, extreme temperatures, and overexertion (Wethers, 2000a).

3.2 PAIN MANAGEMENT IN THE EMERGENCY DEPARTMENT

Sickle cell disease (SCD) is associated with vaso-occlusive pain crises that cause chronic pain, organ failure, significant morbidity, mortality and impaired quality of life. These pain crises

often require frequent visits to the emergency room and admissions to the hospital. It has been estimated that charges of \$36 million per year is a result of hospital use in this population and that another \$14.4 million per year is a result of emergency department (ED) use alone (Aisiku et al., 2007). Vaso-occlusive crises account for 79-91% of emergency room visits and 59-68% of all hospital admissions in sickle cell patients. Most admissions last on average from 8-11 days (Jacob, 2005 & 2008).

Vascular occlusion is the hallmark of sickle cell disease. A severe, acute pain episode is defined as one that requires treatment with narcotics for four or more hours in a medical facility. If a patient experiences three or more of these acute pain crises he/she is classified as having severe SCD (Ballas, 2005). At initial presentation, about 50% of patients show objective signs of pain crisis; these include fever, leukocytosis, joint effusions, and tenderness. As the pain crisis develops, objective laboratory signs are evident in most patients; the percentage of dense red blood cells increases while there is a decrease in red blood cell deformability, many patients develop hyperhemolysis, decreased hemoglobin levels, and an increased reticulocyte count (Ballas, 2005).

When considering how to manage pain, it should be kept in mind that prevention of pain is always better than treatment (Jacob & Mueller, 2008). There is some evidence that acute painful crises can lead to long-term health consequences, even when the vaso-occlusive episode appears to have been resolved. In untreated pain, injured tissue can send sensory input to the spinal cord neuron causing any subsequent responses to be enhanced. If this severe pain goes untreated, it is possible that long-lasting changes in the nerve cells may occur that lead to the development of chronic pain (Jacob & Mueller, 2008). In addition, when pain is severe and established, it is often more difficult to control. Studies have found that persistent pain has an

underlying physiological mechanism that is different from the physiology of prolonged acute pain (Jacob & Mueller, 2008). It is therefore very important for patients with SCD to receive effective and aggressive treatment as soon as possible.

The standard form of treatment for pain crises in SCD is by the use of narcotics such as morphine and hydromorphone (Givens, 2006); however effective pain management is complex and requires a thorough knowledge and understanding of the issues surrounding chronic pain management of an incurable disease. Some of these issues include understanding the pathophysiology of SCD, the pharmacology of the analgesics, and how the attitude of the physician may affect care and treatment (Ballas, 2005).

Effective pain management in the treatment of sickle cell disease should be personalized for each patient in order to avoid making generalizations about patients and their response to analgesics. For example, a patient who has a lot of experience to opioids may experience less pain relief from the standard dose, while a patient who has little experience with opioids may experience over sedation (Ballas, 2005). Physicians treating these patients should have basic knowledge about their patients, including age, sex, diagnosis, complications, and previous pain management methods. Additionally, physicians should know information in order to assess the psychosocial and socioeconomic conditions of the patient; this may include knowing the patient's education level, family structure, housing conditions, ethnicity, religion/beliefs, and perception of the severity of his/her disease (Ballas, 2005; Wilson et al., 2003). Sickle cell disease is complex and pain experiences may be affected by social, cultural, and psychological factors rather than only pathophysiologic factors. Besides the issues discussed above, pain management in SCD may be more effectively managed by following four steps: assessment, treatment, reassessment, and adjustment (Ballas, 2005).

3.2.1 Four steps for effective pain management

Assessment is the most important factor in effective pain management. Since pain experiences are subjective, patient's self-report is necessary in during evaluation (Ballas, 2005). This self-report should include descriptions of the intensity, quality, location, distribution, onset, duration, and factors that help in the relief of the pain or that aggravate the pain. Assessment should also include determining the presence of other complicating factors (for example, infection), family member's reports, and vital signs, including: temperature, respiration rate, pulse, blood pressure, and pulse oximetry. Pain intensity may be measured by a variety of scales such as a numerical, visual, or verbal scale, or the Baker-Wong faces scale for children (Ballas, 2005). The same scale should be used routinely to allow the patient and healthcare provider to become familiar with the scale and what ratings mean for the particular patient. The goal of assessment is to establish a baseline level for which effective pain management will be compared to (Ballas, 2005).

Following a baseline assessment, a treatment should be discussed that is personalized for the individual. Factors that should be considered are the choice of analgesic, the dose, and the route of administration. As treatment is progressing, the patient should be reassessed to determine how well the pain is being managed. Based on this reassessment, adjustments should be made to better manage the individual's pain. This may include increasing the dose of analgesic to better control pain, decreasing the dose of analgesic as pain resolves, and identifying any adverse effects of the treatment or any complications from the disease. These steps should be repeated as necessary until pain has resolved (Ballas, 2005).

3.2.2 Methods and medications used in sickle cell pain management

Pain that is mild to moderate in severity may be treated at home using a combination of nonpharmacologic and analgesic options (Ballas, 2005). Mild pain may be lessened by the use of non-pharmacologic methods and/or non-opioids. More severe pain may include the use of an opioid with or without an adjuvant. Severe, acute pain may be treated in a medical facility with the use of intravenous or intramuscular analgesics (Ballas, 2005). A combination of long- and short-acting opioids have been found to work best in managing both chronic sickle cell pain and frequent acute pain (Ballas, 2005). Day hospitals are an option in some cities with experts in SCD pain management available to evaluate patients promptly, without the delay commonly found in emergency departments (Ballas, 2005; Benjamin et al, 2000). Day hospitals have been found to reduce the number of unnecessary admissions to the hospital (Benjamin et al, 2000; Jacob & Mueller, 2008).

3.2.2.1 Non-pharmacologic management of pain

Non-pharmacologic management of pain may include methods such as cutaneous stimulation, massage, relaxation, heat, cold, and vibration, distraction, music, guided imagery, self-hypnosis, self-motivation, acupuncture, and biofeedback (Ballas, 2005).

3.2.2.2 Non-opioids

Non-opioids that may be used for the management of pain in patients with SCD include acetaminophen, non-steroidal anti-inflammatory agents (NSAIDs), topical agents, tramadol, and corticosteroids (Ballas, 2005). Non-opioids have a ceiling effect where above certain doses there is no increased analgesic effect. Acetaminophen is an analgesic without anti-inflammatory

properties; high doses may cause liver damage. NSAIDs are analgesics that also have anti-inflammatory properties; adverse effects include gastropathy, nephropathy, and hemostatic defects. NSAIDs should not be administered to individuals with renal disease or a history of peptic ulcer disease. Tramadol (Ultram) is an analgesic unrelated to opioids but with opioids and anti-depressant properties; it has been found to be effective in patients with mild to moderately severe sickle cell related pain (Ballas, 2005).

3.2.2.3 Opioids

Opioid agonists are commonly used in the management of pain in individuals with SCD (Ballas, 2005). They work by reducing or modifying the perception of pain by the central nervous system. They have fewer adverse effects than NSAIDs; however, their use in patients with SCD is associated with the spread of myths regarding addiction and drug-seeking behavior (Ballas, 2005). Adverse effects include itching, nausea, vomiting, sedation, respiratory distress, and seizures. Opioids do not have a ceiling effect; therefore the only reason to limit administration of opioids is due to the adverse effects listed above. These medications can be given in a variety ways, including orally, intravenously, transdermally, subcutaneously, or intramuscularly, and also by a variety of methods, including continuous intravenous drip, patient controlled analgesia pump, or by injection (Ballas, 2005).

3.2.2.4 Adjuvant Therapies

Adjuvant therapies include antihistamines, antidepressants, benzodiazepines, and anticonvulsants. These medications work to increase and sustain the effects of opioids and lessen their side effects (Ballas, 2005). In addition, some also have mild analgesic properties. Adjuvants

should be administered carefully and closely monitored as they have their own side effects and may potentially worsen complications already present in patients with SCD (Ballas, 2005).

3.2.2.5 Hydroxyurea

Hydroxyurea is a cytotoxic medication that has been shown to reduce the number of pain crises in individuals with moderate to severe SCD by 50% (Ballas et al., 2006; Charache et al., 2005; Stuart & Nagel, 2004; Wilson et al., 2003). The mechanism of how hydroxyurea works to reduce pain crises is not entirely known, but some studies have shown that heme groups can oxidize hydroxyurea to produce nitric oxide (NO) free-radicals; these free-radicals mediate the activation of soluble guanylyl cyclase, which in turn increases γ -globin expression and HbF synthesis (Cokic et al., 2003). In addition, hydroxyurea may lower white blood cell, reticulocyte, and platelet counts, improve red blood cell hydration, increase NO production, and decrease RBC adhesiveness (Hankins et al., 2009). Fetal hemoglobin inhibits sickling of the RBCs due to its lack of β -globin chains; it is composed of two α -globin and two γ -globin subunits. Levels of HbF sustained over 20% are associated with reduced clinical events in patients with SCD; while, decreased concentration of HbF has been recognized as a predictor of early mortality in patients. Clinical observations have found that increased HbF due to hydroxyurea has significantly reduced the frequency of pain episodes, as well as led to reductions in the frequency of acute chest syndrome and the number of transfusions required. The long-term effects of hydroxyurea are not currently known (Charache et al., 2005) and no evidence indicates that there is an increased risk for malignancies. Studies of the long-term effects are ongoing (Hankins et al., 2009).

3.2.3 Improved pain management in the ED

Despite the availability of national guidelines that address the ethical issues of pain management (published by the Joint Commission for the Accreditation of Healthcare Organizations (JCAHO) and the American Pain Society; Jacob et al., 2003; Todd et al., 2007; Yagood et al., 2000), patients with SCD often receive suboptimal pain control, especially during acute painful episodes (Jacob et al., 2003; Maxwell et al., 1999; Rupp & Delaney, 2004). This may be a result of physicians' limited knowledge about SCD or a lack of training in chronic pain management (Aisiku et al., 2007). In addition, sickle cell patients may be stereotyped as being drug seekers or abusers by health care professionals who are not familiar with SCD (Aisiku et al., 2007; Jacob, et al., 2003; Maxwell et al., 1999). This mistrust may lead health care professionals to attempt to excessively control the patient's pain management. Besides mistrust between the physician and the sickle cell patient, access to care may be limited by the patients' socioeconomic status. The education and income levels of SCD patients are similar to that of other African-Americans, however, unemployment rates are higher and the personal income rates are lower for individuals with SCD (Aisiku et al., 2007).

In cases where patients are rarely admitted to the hospital, it has been found that physicians may actually over-treat sickle cell pain (Maxwell et al., 1999), suggesting that physicians are not only concerned about addiction, but also about issues of trust, control, and patient involvement (Maxwell et al., 1999). This lack of patient involvement in pain management decision making may undermine self knowledge and self reliance, thus reducing the patients' ability to management his/her pain independently; repeated cycles of control and neglect lead to mistrust of the healthcare professional and anxiety about receiving satisfactory pain

management. Previous studies have found that sickle cell patients experience under treatment of pain, lack of involvement in treatment decisions, and stigmatization (Maxwell et al., 1999).

Patient dissatisfaction may affect compliance or the utilization of treatment and resources (Aisiku et al., 2007). Satisfaction may be measured through the use of surveys that ask individuals to rate the overall care and treatment they received (Margaret et al., 2002). In addition, individuals may be asked to rate how respectfully they were treated. Ratings of respect may indicate professionalism of the health care provider and satisfaction with not only physical treatment, but psychosocial and emotional treatment (Margaret et al, 2002; Maxwell et al., 1999; Duff, 2004). Most recurrent acute pain episodes are managed in the ED (Aisiku et al., 2007), thus the ED is a good place to begin improving pain management for patients with SCD.

Some studies have found that establishing early intervention and/or preventative protocols for treatment of pain may help to better control pain in patients with SCD (Jacob & Mueller, 2008). These interventions may include having protocols in place in an ED for aggressive early pain management and hydration. If pain is better controlled, chronic pain may be less likely to develop (Jacob & Mueller, 2008) and patients may feel more satisfied with their pain management.

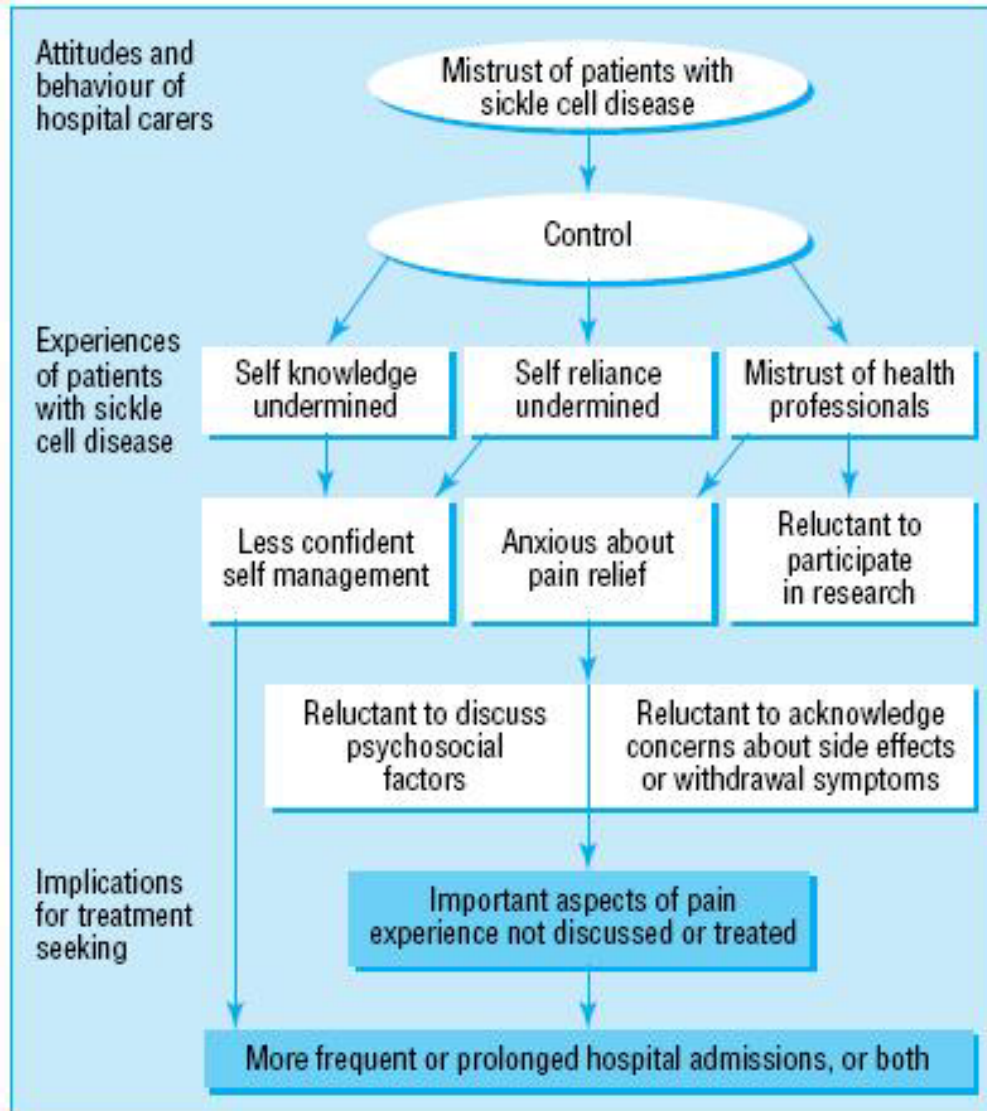


Figure 4: How hospital experiences may adversely influence individual pain management

(Maxwell, et al., 1999)

4.0 MATERIALS AND METHODS

4.1 SPECIFIC AIM I: RETROSPECTIVE DATA

IRB approval was obtained for an exempt study (Appendix B). Data for this study were obtained from the Pediatric Health Information System (PHIS), an administrative database that contains the inpatient data from 40 not-for-profit, tertiary care pediatric hospitals in the United States. These hospitals are affiliated with the Child Health Corporation of America (CHCA; Shawnee Mission, KS), a business alliance of children's hospitals. Data quality and reliability are assured through a joint effort between the CHCA and participating hospitals. The data warehouse function for the PHIS database is managed by Thomson Healthcare (Durham, NC). For the purposes of external benchmarking, participating hospitals provide discharge data including demographics, diagnoses, and procedures. Data are deidentified at the time of data submission, and data are subjected to a number of reliability and validity checks before being processed into data quality reports. Data are accepted into the database once classified errors occur less frequently than a criterion threshold. If a hospital's quarterly data is unacceptable according to these limits, all of their quarterly data is rejected; however, this data can be resubmitted and reevaluated prior to inclusion in the database. For this study, data from four hospitals was included. This data was used, in aggregate, to compare various aspects of emergency department

visits and admissions of sickle cell patients with data from the Children's Hospital of Pittsburgh (CHP).

Individualized pain plans for each patient were put in place at Children's Hospital of Pittsburgh in 2002-2003. These include a personalized medication list for emergency visits and in-patient stays. PHIS data summaries for admissions, readmissions, average length of stay, discharges and days per patient, and CMI were provided, and were used to compare CHP to a selected group of hospitals. These hospitals were chosen due to their similar programs and patient populations. Data was specifically collected for admissions due to pain crisis and excluded patients with acute chest syndrome. Additionally, two medical record numbers were excluded from the CHP data because, based on experience with these patients, they were known to be outliers. The statistical program SPSS was used, with the help of Dr. Eleanor Feingold, to perform logistic binomial regression to determine whether there has been a significant change in admission rates since individualized pain plans for each sickle cell patient had been implemented in 2002 to the present between CHP and other hospitals.

4.2 SPECIFIC AIM II: CURRENT SATISFACTION LEVELS

In addition to exempt IRB approval for evaluating retrospective data, expedited IRB approval was obtained to investigate current patient and parent satisfaction levels with pain management in the emergency department (Appendix A). Permission to use a template for patient and parent satisfaction surveys was obtained from Dr. Jerris R. Hedges (Margaret et al., 2002). These templates were modified to include some additional questions relevant to the Children's Hospital of Pittsburgh and study aims (Appendices C-E).

During the process of obtaining IRB approval, meetings were held with members of the ED staff to try to determine the best method of contacting and obtaining consent from patients. At that point, it was agreed that contact would be made when the patient came into the ED. When this method was put into place following IRB approval, it was found that it was difficult to catch many patients and to coordinate the PI meeting with the patients in the ED before being discharged. An IRB modification was submitted, and approved, at this point to allow contact to be made at any point following an ED visit by phone or in person; this included visiting the patient in sickle cell clinic, while they were in-patient, or while they were in the ED. A modification was also submitted and approved to waive signed consent in cases where surveys were conducted over the phone.

The PI was notified when patients came into the ED each week. If the PI was not able to meet the patient in the ED, their name was added to a list that recorded the day the patient came into the ED. In addition, a query was run through the sickle cell database to find patients who had visited the ED in the past two years. Each week, the PI cross-checked the list of patients seen

in the ED with the list of patients coming in to sickle cell clinic and the list of patients in house provided by the administrative assistant. The PI would then meet with these patients to describe the study, obtain consent, and administer the surveys. If patients were not scheduled for a clinic visit in the near future, they were called, the study was described, and they were asked if they were interested in participating. Consent forms were then sent in the mail and the patient was encouraged to call if there were any questions or if they did not want their information used in the study.

Data was analyzed using SPSS; descriptive statistics and p-values were obtained for each survey question for each age group. Values were also compared for children's responses versus parent's responses using independent T-tests.

5.0 RESULTS AND DATA ANALYSIS

5.1 SPECIFIC AIM I: EVALUATING RETROSPECTIVE DATA

Data from CHP and the Pediatric Health Information System (PHIS) were obtained from David Kaizmer, Systems Analyst III with CHP's Quality Services. Data Summaries for admissions, readmissions, average length of stay, discharges and days per patient, and case mix index (CMI) were used to compare CHP to a selected group of hospitals. It was believed that admission rates, and possibly readmission rates, would be the most accurate predictor of patient care. This was assumed because length of stay, discharges per patient, and days per patient (Appendix G) have the potential to be biased to show a positive trend by unsatisfactory care. For example, a patient may be discharged before he/she is ready leading to a shorter length of stay and days per patient. These numbers may reflect well on the hospital, but not accurately gauge patient care and satisfaction. On the other hand, if admission rates are decreasing, it is likely a reflection on care and pain management that patients are receiving in the emergency department. Readmission rates were also looked at since low readmission rates may indicate that pain is well enough controlled that the patient does not need to return to the hospital.

Data for admission rates is shown in Appendix G and Figure 5; data for readmission rates is shown in Appendix G and Figure 6. The table of information includes the proportions of admissions and the total number of patients seen. These proportions were used for statistical

analysis by binary logistic regression to determine a p-values and whether there was a trend seen over the years and between the hospitals.

Table 1 summarizes the results that were found for admission rates. Binary logistic regression found significant differences at $\alpha=0.05$ for admission rates between CHP and PHIS, as well as significant differences in admission rates over the years analyzed for both CHP and PHIS. Finally, there was a significant difference between the hospitals from 2002 to 2008, quarter three. Readmission rates were found to not show a significant trend (Table 5). However, rates were relatively low over the years for both hospitals, ranging from 3.1% to 8.0% at CHP and from 3.9% to 6.9% for the PHIS hospitals.

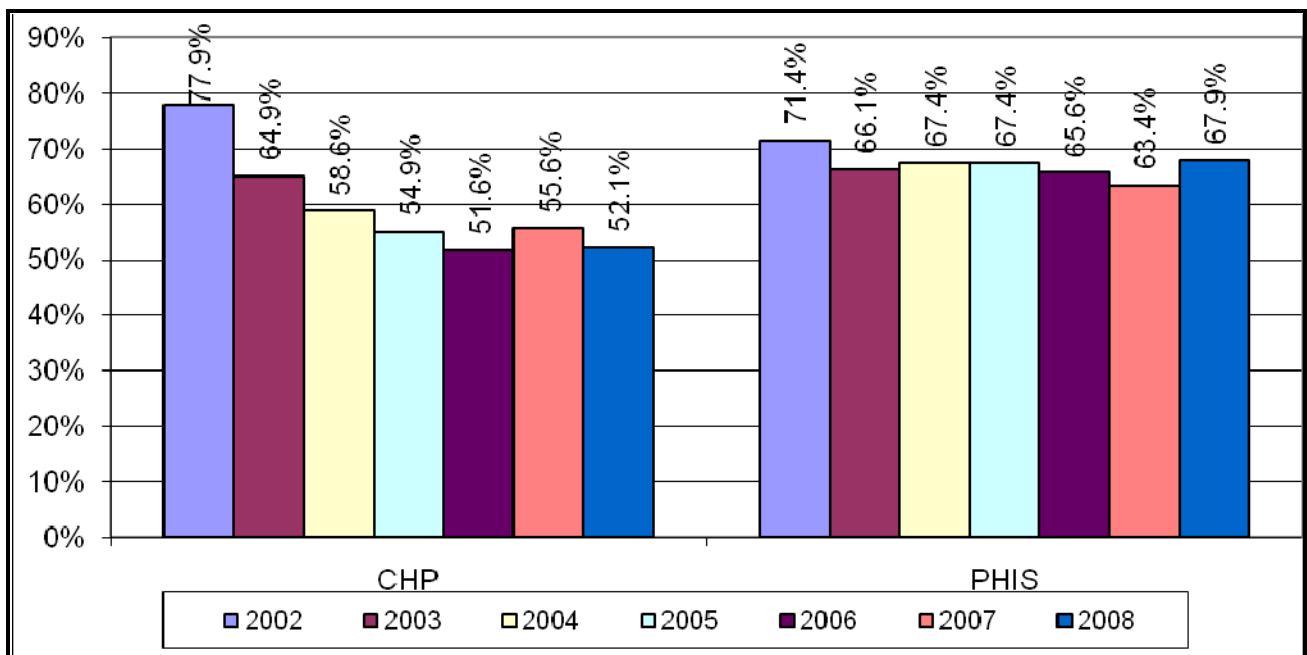


Figure 5: Admission data for CHP and PHIS from 2002 to 2008, quarter 3

Table 1: Admission rates comparison between CHP and PHIS over time

	P-value	Interpretation at $\alpha=0.05$
Hospital	<0.05	Significant difference between CHP and PHIS
Year: CHP	<0.05	Significant difference over years
Year: PHIS	<0.05	Significant difference over years
Interaction	<0.05	Significant difference over years between hospitals

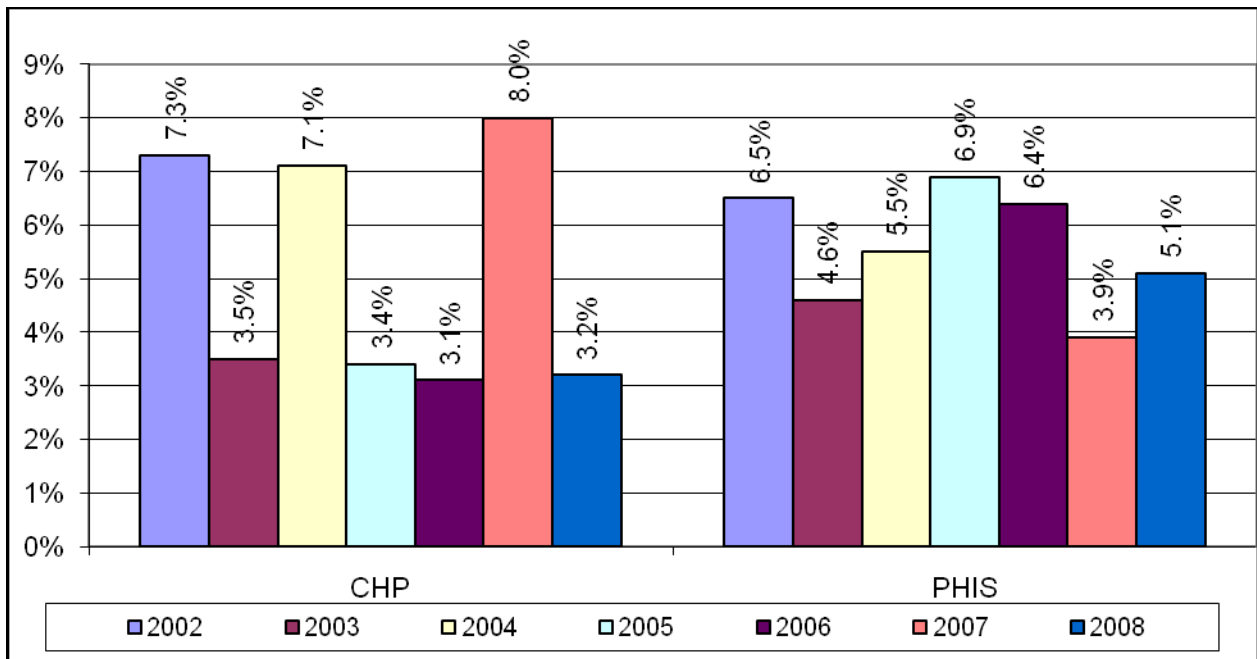


Figure 6: Data of readmission rates as a graph

5.2 SPECIFIC AIM II: EVALUATING CURRENT SATISFACTION

5.2.1 Demographics

Three similar surveys were administered to patients and their parents, depending on their age (Appendix C-E). Basic demographics of the study population are shown in table 2. Raw data for all groups are shown in Appendix H.1.

Table 2: Demographics of study participants

Age Range	Number	Male	Female
5-11 years	7	1	6
12-17 years	15	3	12
18+ years	14	5	9
Parent	31	0	31
Total	67	9	58

There were more female participants in each category; this makes sense for the parent category as women more often tend to be the primary caregiver. However, the reason for more females than males in the other categories is unexplained.

5.2.2 Data for Children Age 5 to 11

For children ages 5-11, four of seven (57.1%) rated overall care and treatment as “very good” or better; qualitative descriptors were correlated to numbers 0 (poor) to 5 (extraordinary). None of the participants in this age group rated overall care and treatment as poor (Figure 7).

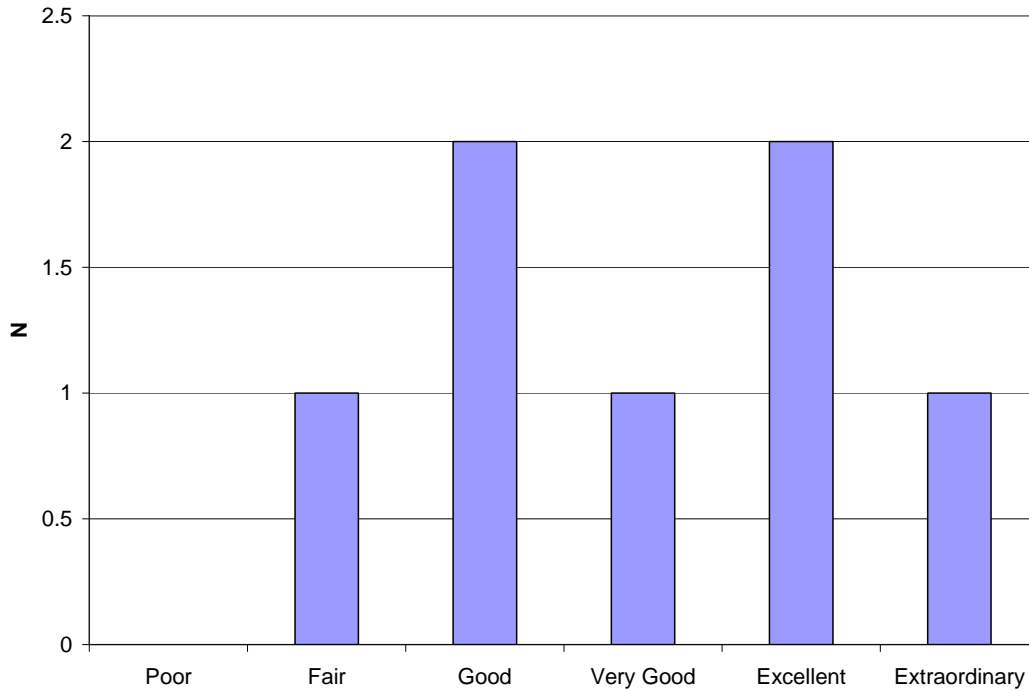


Figure 7: Overall Care and Treatment Ratings (Ages 5-11)

The rest of the questions for this age group were based on the Baker-Wong Faces scale (figure 8). This scale was chosen because the surveys obtained and modified from Margaret et al. (2002) used this scale.

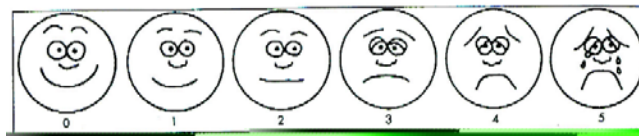


Figure 8: Baker-Wong faces scale

There was a significant change in the pain scores before coming in to the ED and after leaving the ED ($p=0.010$; Appendix H.2). Only one patient reported having a level 4 pain on average each day; six experienced little (1) to no (0) pain. On average, patients were not scared about coming in to the ED and almost all the participants' fear had resolved by the time they left.

5.2.3 Data for Children Age 12 and Up

For children ages 12 and over, 20 of 29 (69.0%) rated overall care and treatment as “very good” or better. Only one of the participants in this age group rated overall care and treatment as poor; there were two who gave a rating of “fair” and six who gave a rating of “good” (Figure 9).

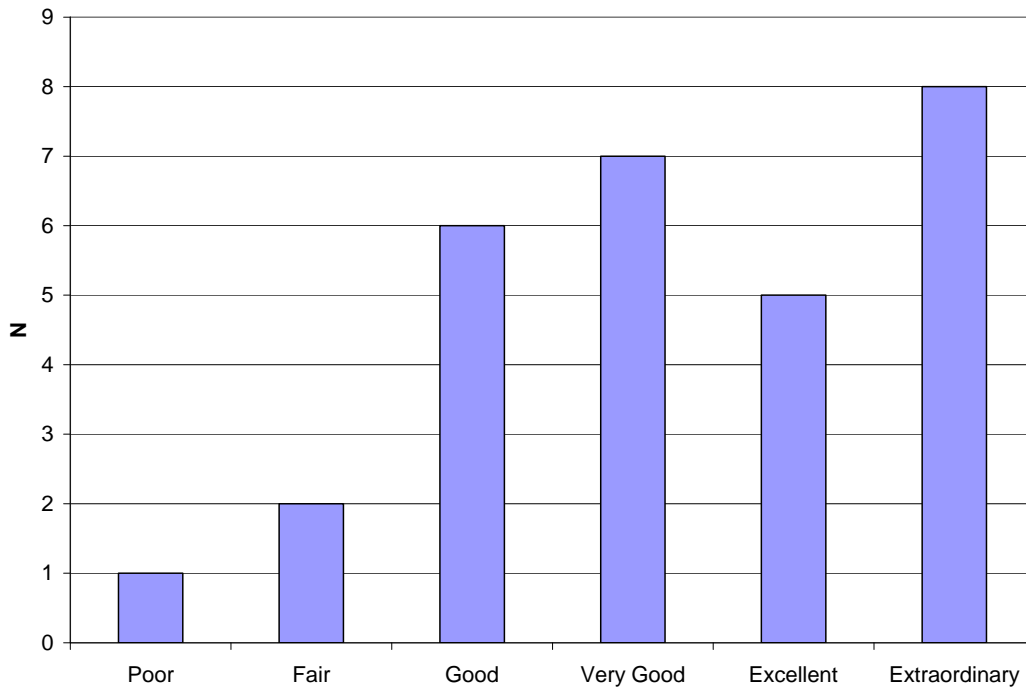


Figure 9: Overall Care and Treatment Ratings (Ages 12-21)

Based on the faces scale, 93.1% of participants rated the niceness of the staff and doctors as a 2 or better. Eighteen patients rated their pain as 5 out of 5 on the faces scale before visiting the ED. After visiting the ED, only 2 patients reported having a 5 out of 5 pain. There was a significant decrease in pain scores compared before and after being seen in the ED ($p < 0.05$; Appendix H.2). Nineteen of 29 participants (65.5%) experienced little to no pain (0 to 2) on average each day.

Sixty-nine percent of participants (20 out of 29) believed that information regarding their pain management was given in a manner “very good” or better. When asked to rate how well their pain was managed there was a range of scores given by participants; 51.7% chose a score of “very good” (3) or better (4, 5) (Figure 10).

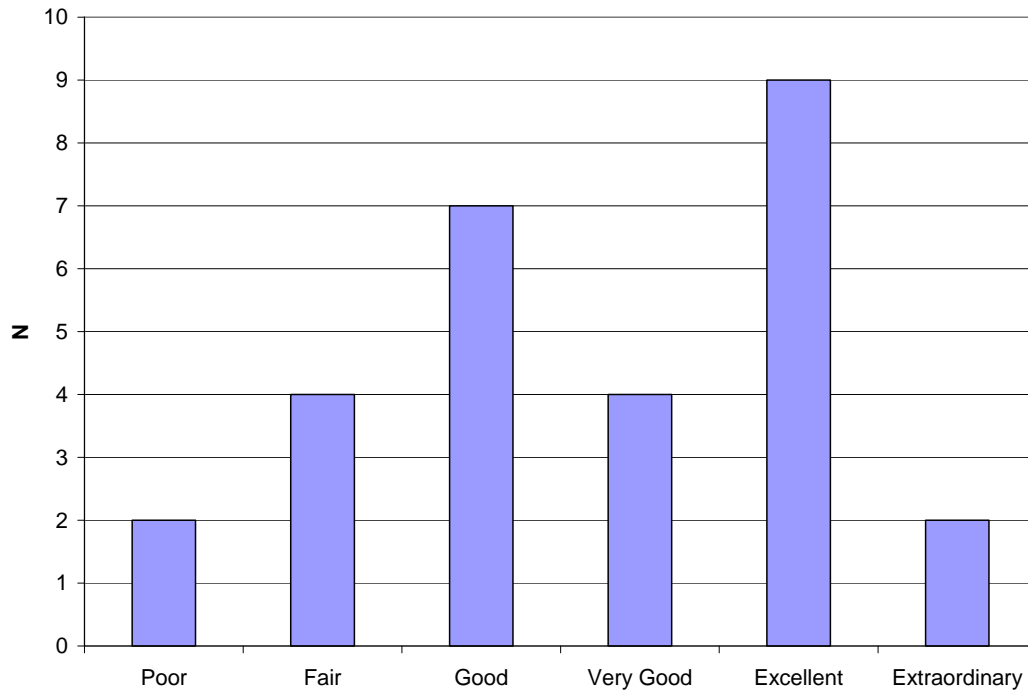


Figure 10: Distribution of Pain Management Ratings (Ages 12-21)

In terms of respectfulness of the doctors and staff who took care of the patients in the ED, 89.7% of patients ages 12-21 gave ratings of “very good” or better (Figure 11).

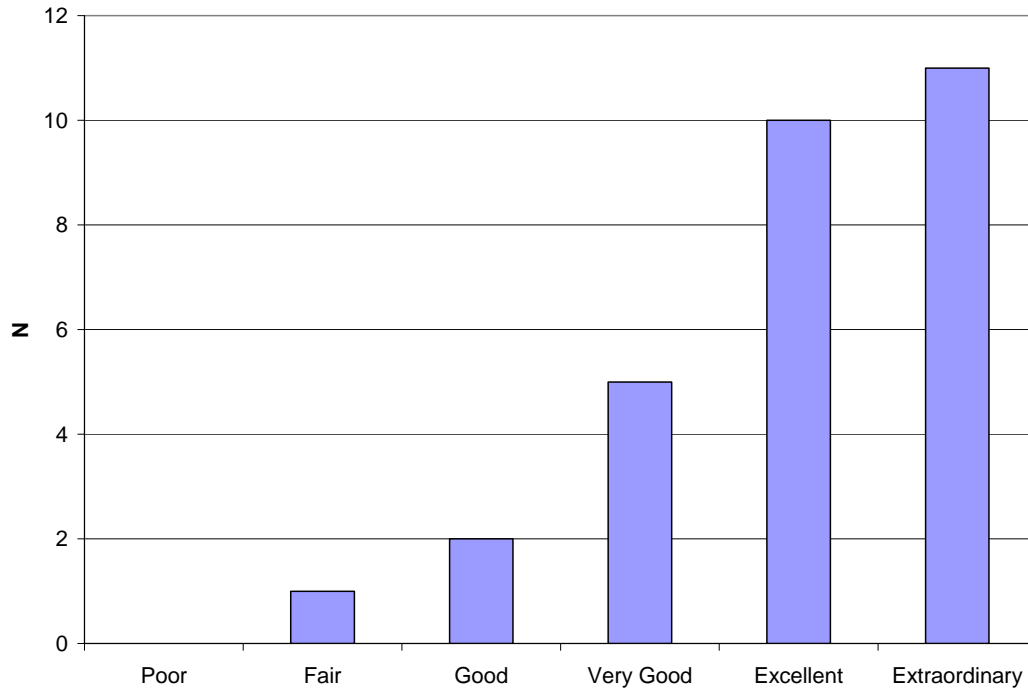


Figure 11: Distribution of Child Respectfulness Ratings

Reported wait times varied greatly; the range of time participants reported spending in the waiting room before being taken into an exam room was from zero to 1470 minutes (24 hours, 30 minutes), with the mean wait time for a room being 70.74 minutes. The median and the mode were 10 minutes; when outliers over 90% were removed the mean wait time was 13.76 minutes with a range of 0 to 150 minutes. The range of time reported for the patient to be seen by a doctor or a nurse once he/she was in an exam room was from zero to 390 minutes (6 hours, 30 minutes), with an mean wait time to be seen of 53.70 minutes. The median and the mode were 20 minutes; when outliers over 90% were removed the mean wait time was 32.83 minutes with a range of 0 to 210 minutes. The time that patients reported waiting to receive pain medication ranged from 5 to 270 minutes (4 hours, 30 minutes); the mean time to receive pain medication was 53.34 minutes (Appendix H.3). The median was 25 minutes and the mode was 10 minutes;

when outliers over 90% were removed the mean wait time was 39.89 minutes with a range of 0 to 180 minutes.

Twenty-seven of 29 participants (93.1%) reported that they would return to the CHP emergency department. Only one participant (3.4%) reported that they would not return to the CHP emergency department, and only one participant reported that they were unsure whether they would return in the future. Twenty-seven of 29 participants (93.1%) reported that they would recommend the ED to a friend. One participant (3.4%) reported that they would not recommend the ED to a friend, and one participant reported that they were unsure whether they would recommend this ED to a friend (Appendix H.1).

5.2.4 Data for Parents

The survey administered to parents of patients with SCD was similar to that given to patients ages 12 to 21. Parents rated the overall treatment and care they received in the ED as “very good” or better in 24 out of 31 (77.4%) cases (Figure 12).

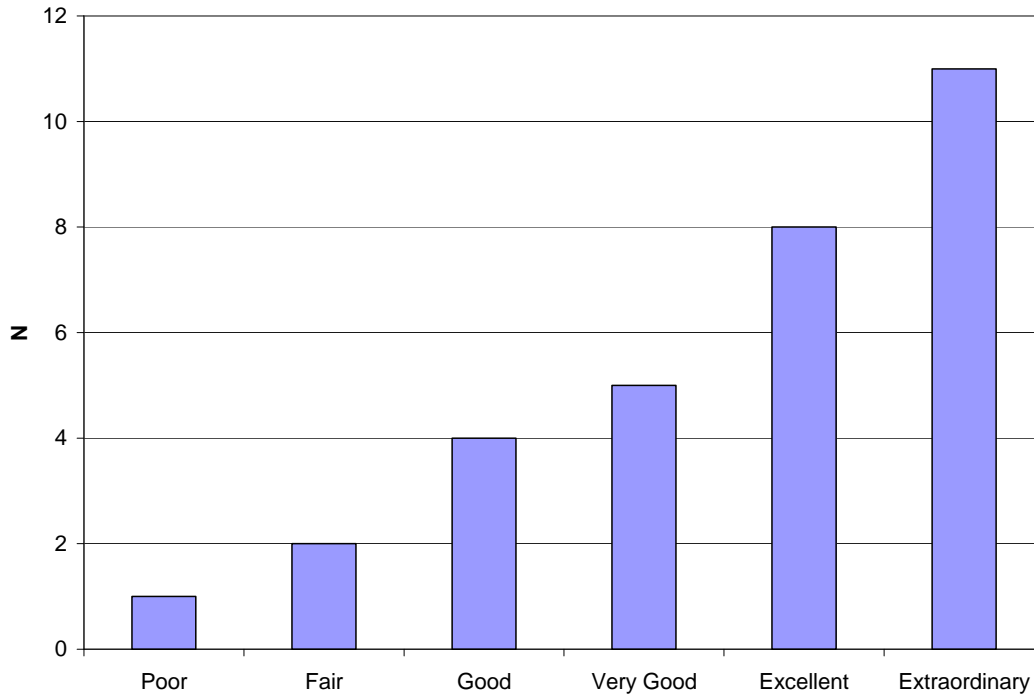


Figure 12: Overall Care and Treatment Ratings (Adults)

Twenty out of 31 parents (64.5%) reported that their child had a pain level of 5 out of 5 on the faces scale before visiting the ED. After being seen in the ED, four parents reported that their child had a 5 out of 5 pain level. There was a significant change in pain scores that parents reported before and after their child was seen in the ED ($p < 0.05$, Appendix H.2). Twenty-seven out of 30 parents reported that their child experienced a level 2 or less amount of pain on a regular/daily basis.

Twenty-two out of 31 parents (71.0%) reported that they were given information regarding their child’s pain management in a manner “very good” or better. Twenty-two of 30 parents (73.3%) believed that their child’s pain management was “very good” or better (Figure 13).

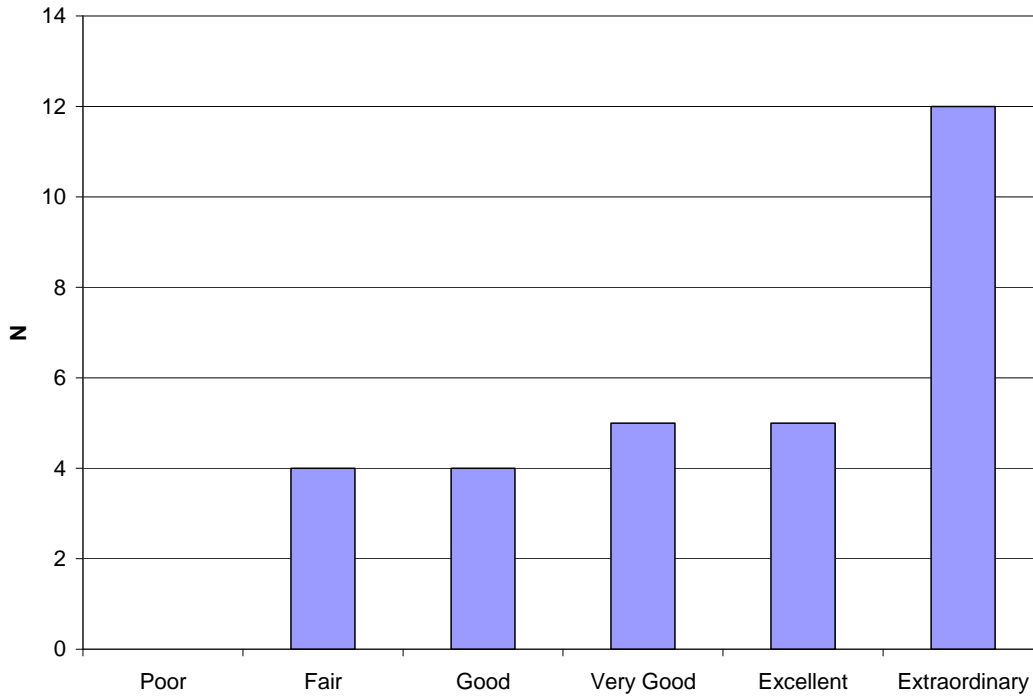


Figure 13: Distribution of Pain Management Ratings (Adults)

The majority of parents (29 out of 31; 93.5%) reported that the doctors and staff who cared for their child were respectful.

Like patients ages 12-21, the waiting rooms times estimated by parents varied greatly. The mean amount of time spent in the waiting room was reported to be 51.02 minutes, with a range from 0 to 660 minutes (11 hours). The median was 10 and the mode was 0 minutes; when outliers over 90% were removed the mean wait time was 13.16 minutes with a range of 0 to 60 minutes. The mean amount of time reported being spent waiting in an exam room to be seen by a doctor or nurse was 14.52 minutes; however, the range was from 0 to 75 minutes (1 hour, 15 minutes). The median was 7 and the mode was 0 minutes; when outliers over 90% were removed the mean wait time was 10.82 minutes with a range of 0 to 37 minutes. Finally, the mean amount of time spent waiting for pain medication was reported to be 43.63 minutes, with a

range from 0 to 360 minutes (6 hours). The median was 20 and the mode was 60 minutes; when outliers over 90% were removed the mean wait time was 24.85 minutes with a range of 0 to 60 minutes. (Appendix H.3).

Ten parents reported that they had been to the ED 3 or more times in the last year. Thirteen parents reported that they had needed to bring their child to the ED 2 to 3 times in the last year; eight parents only had to bring their child to the ED once in the last year (Figure 14).

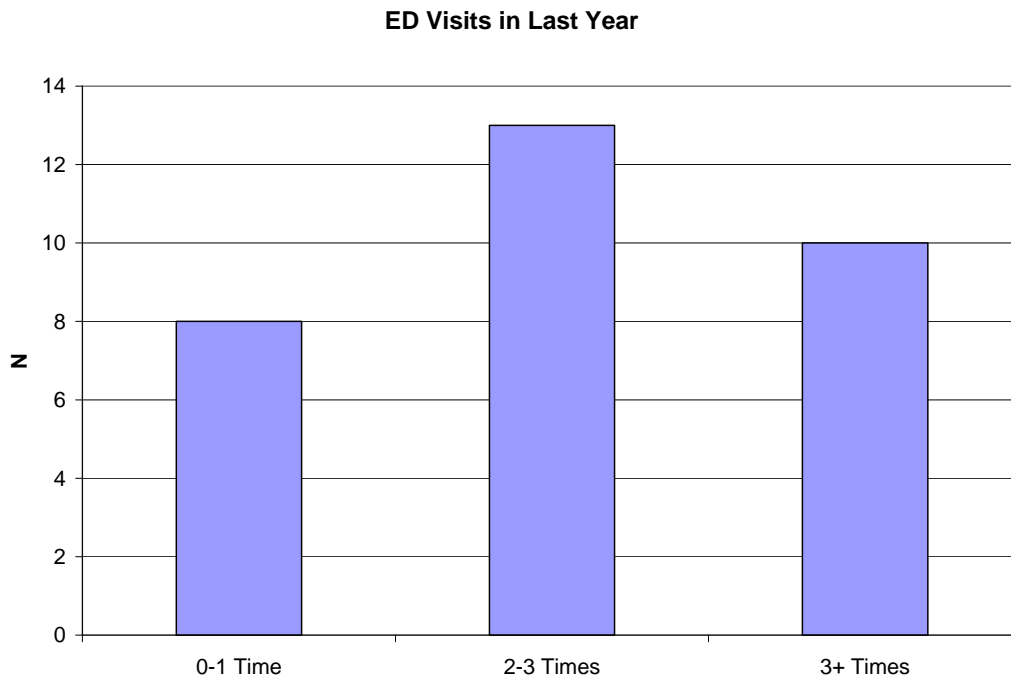


Figure 14: ER Visits Reported in the Past Year

There was only one parent who reported that they would not recommend the CHP emergency department to a friend and only one parent who was unsure if they would recommend this ED. Only one parent reported that they would not return to the CHP emergency department in the future. All other parents reported that they would both recommend the Children’s Hospital of Pittsburgh’s ED and would return in the future. (Appendix H.1)

5.2.5 Qualitative Data

A number of participants took the time to discuss and write comments about what they felt could be improved in their care and pain management. One patient, who rated overall care as “good,” stated that “one of the doctors [I] had didn’t seem like he really believed that [I] was in pain, and he didn’t follow [my] pain plan.” There were not any other similar comments, however, another patient alluded to doctors not reviewing her pain plan; her comment was that there “should be a record of all the medicines [I] take so [I] don’t have to say them every time a new doctor comes in.” While this patient rated overall care as “excellent,” she did indicate that it took four and a half hours to receive medication for her pain. A different patient wrote that “staff doesn’t seem to know as much about sickle cell or treatment of it than [I] expected;” she rated overall care as “good.”

One of the most frequently written-in comments was regarding the time it took to be seen. A number of patients felt that the time it took to be seen was too long and expressed dissatisfaction due to the wait. One patient felt that “there are not enough nurses and doctors to tend to all the patients that come in to the ED;” this patient reported that it took six and a half hours to be seen by a doctor or nurse and rated overall satisfaction as “fair.” Another fairly common comment was that there should be more communication between the health care providers and the patients/parents. Patients and parents both commented about feeling frustrated at answering the same questions from different doctors while they were in severe pain and/or waiting for pain medication. One parent commented that, “[I] think most questions asked during time of trying to get medication started for patient could simply be asked if there are any changes instead of answering 25 questions while your child is in severe pain.” Additionally, a couple

patients mentioned that it was difficult to get physicians or staff to give them a direct answer or to get information about their treatment or that the provider was rude when questions were asked.

A number of both patients and parents expressed satisfaction with care and included positive comments regarding their treatment and pain management. One parent commented that CHP was an excellent hospital where professional training is evident and that everyone was helpful and accommodating. Another parent noted that she has had great hospital ED experiences; both parents rated overall care and treatment as “extraordinary.”

5.2.6 Overall Comparisons

Children ages 5-11, 12-21 and parents gave similar ratings for overall treatment and care they received in the ED ($p=0.49$). There was also not a significant difference between the ratings children ages 12-21 and parents gave for how well information was given regarding their pain/pain management ($p=0.47$). Children (ages 12-21) and parents also gave similar ratings for how respectful the doctors and staff were ($p=0.55$). Additionally, children ages 5-11 and children ages 12-21 gave similar ratings when asked how nice the doctors and nurses were ($p=0.22$) (Appendix H.4).

Parents and both age groups of children also gave similar pain ratings, before being seen in the ED ($p=0.91$), after leaving the ED ($p=0.16$), and on average each day ($p=0.22$). However, there was a significant difference between children ages 12-21 and parent ratings for how well pain was managed ($p=0.044$). Parents gave a more positive rating for pain management (3.57; 3=“Very Good” 4=“Excellent”) than their children (2.78; 2=“Good”) (Appendix H.4).

Parents and children ages 12-21 had similar estimates of time spent in the waiting room before being taken into an exam room and of the amount of time to receive pain medication

($p=0.922$; $p=0.103$, respectively) . However, there was a significant difference in the estimate of how long it took to be seen by a doctor or a nurse ($p=0.014$). On mean without including outliers over 90%, children estimated that it took 32.83 minutes to be seen while parents estimated that it took 10.82 minutes to be seen (Appendix H.4).

6.0 DISCUSSION

6.1 SPECIFIC AIM I: EVALUATING RETROSPECTIVE DATA

Analysis of retrospective data from the Children's Hospital of Pittsburgh (CHP) and the Pediatric Health Information System (PHIS) was performed to draw conclusions about whether patient care has improved in the past few years as knowledge about sickle cell disease has increased. At CHP, individualized pain plans were implemented in the emergency department (ED) in 2002-2003. These pain plans contain the most recent record of medications each sickle cell patient has received on their last visit to the ED. It was believed that these pain plans would improve knowledge and understanding of sickle cell and help in the care and treatment of patients with SCD who present to the ED.

Data from CHP and PHIS, including admission rates, were obtained through the Child Health Corporation of America (CHCA). Hospitals other than CHP were chosen due to their similar pediatric SCD programs and populations. Admission rates were picked as an indicator of patient care because it was believed that if admission rates decreased it is likely a reflection of how well patients were managed in the ED.

Analysis of admission rates found that there was a significant difference in rates from 2002 to the present for both CHP and PHIS; it was also found that there was a significant difference in admission rates between CHP and PHIS. The time of highest admission rates at

CHP was in 2002; over the years, the number of admissions has decreased significantly. This is an indication of improved treatment and care in the ED as fewer patients should be admitted if their pain is being well managed in a timely manner. Improved treatment and care may indicate increased knowledge about SCD by ED staff.

Results of the retrospective data analysis also indicate that the use of individualized pain plans has been an important part of improving patient care. Beginning in 2002, when these plans were first implemented, admission rates for CHP were almost 78%. By the end of the third quarter of 2008, six years after individualized pain plans were established, admission rates had dropped to about 52%.

6.2 SPECIFIC AIM II: EVALUATING CURRENT SATISFACTION

Patient and parent satisfaction surveys from Margaret, et al. (2002) were adapted to measure satisfaction with pain management in the Children's Hospital of Pittsburgh emergency department. The mean rating of overall care and treatment given by children ages 5-21 and parents was a 3.30, where a rating of 3 correlated with "very good" and 4 with "excellent." There was not a significant difference between the ratings that were given by parents and their children who were seen in the ED. Additionally, parents and children rated the respectfulness of ED physicians and staff as a 3.98. These ratings indicate that parents and children who are treated in the CHP emergency department are satisfied with care and pain management.

A significant difference was found in parent and children's ratings of how well pain was managed. Parents gave a more positive rating than children did. This may be because the parents

are not the ones who were experiencing the pain and waiting for the treatment; they only saw that pain was usually resolved by the time they left the ED.

It was also found that ratings of patient's amounts of pain decreased significantly from before they came in to the ED compared to when they left the ED. This is likely to be a cause of many of the patient's satisfaction levels with care. We only evaluated patients who came to the ED with pain and it is beneficial to know that the majority of patients experience resolution of their pain by the time they leave the ED. During discussions with the patients it was common for the patients who were admitted from the ED to still have a higher level of pain. It would be interesting for any future surveys to include a question on whether the patient was admitted in order to keep track of this information.

Comments written in at the end of the surveys by patients and parents varied. A number of participants indicated that they were satisfied with overall care and felt like the Children's Hospital ED had excellent service. However, there were some participants who wrote comments that the staff did not seem knowledgeable about SCD, or that the wait was too long, or that pain plans were not followed. Overall, individuals with negative feedback were less common than satisfied participants and most seemed to report that their negative experience was limited to one particular ED visit.

Results from this study support previous work found in the literature. Patients with SCD have improved outcomes when treatment and care is personalized and when their pain management is designed specifically based on their past experiences. Additionally, if staff appeared to be unknowledgeable about SCD, patients were less satisfied with care.

Based on surveys and talking with patients and parents about their satisfaction with pain management in the ED, it seemed like participants were often most concerned about how quickly

they were seen and how soon pain was brought under control. In all age groups a majority of participants gave positive ratings regarding their overall treatment and care and seemed to be fairly satisfied with their pain management.

6.3 FUTURE WORK

Future work on this project should include collecting more data from patients, and their parents, who have recently been to the ED with pain. It may also be interesting and helpful to add a question on whether the patient was admitted to the hospital. Answers to the question may explain the cases where there was no, or very little, change in pain scores.

If data is continuing to be collected, a quality improvement program should be designed while the last participants are being surveyed. This quality improvement program should consider how to best educate ED physicians and staff about sickle cell disease, its management, treatment, and how to care for patients with SCD. Information that may be included could be the pathophysiology of SCD, how SCD is inherited, the signs/symptoms of a vaso-occlusive pain crisis, triggers of a pain crisis, the clinical effectiveness guidelines for SCD pain management, or other complications of SCD. Possible methods of how a quality improvement program might be implemented may include an in-service training breakfast/ lunch for staff and/or hanging posters about SCD in the staff areas of the ED.

After the quality improvement program has been in place for a while, patient satisfaction should be reevaluated. This could be done by the administration of the same surveys, with any additional questions that may be deemed necessary. Scores from before and after the quality improvement plan was implemented may be compared to see if there has been a significant

change in patient and parent satisfaction with pain management. Additionally, it would be interesting to reanalyze the retrospective data again to see if admission rates decrease further.

6.4 LIMITATIONS AND OTHER CONSIDERATIONS

One limitation of this study is the small sample size. The study started off slow as it was difficult to contact patients under the original IRB submission. Restrictions had been placed on how long after their ED visit patients could be contacted, the method of contact, and the informed consent process. It took a while to work out the best way to resolve all of these issues. In the beginning, patients could only be contacted in the ED or if they had been admitted. If they had been admitted, it was difficult getting informed consent signed as many parents did not stay in the hospital with their children. In the ED, patients occasionally did not feel up to participating; when these patients were called at a later time, some still were not interested in talking, and given the original three day limitation of contact, surveys were unable to be obtained.

The expedited IRB submission went through a few modifications in order to allow a broader method of participant contact. The final modification allowed patients to be contacted by phone, any time after being seen in the ED, and without written consent. This helped facilitate the contact of more patients over a longer time range. Before written consent was waived, it was difficult to sign-up any underage participants; the majority were over 18 years old and did not have a parent accompanying them. However, another limitation was run into when calling patients. Many phone numbers listed in the patient database were disconnected or wrong numbers. This made it difficult to reach the number of patients that was desired. In addition, if

families were reached, many parents seemed uncomfortable having their children answer survey questions over the phone.

Another limitation of this project was due to the extended time range added into the final modification. While a patient could be contacted any time after they had been to the ED, there was a limit of how well patients would remember their visit. A list of patients from who had been to the ED in the last two years was generated from the sickle cell database. Patients were removed from the list if they were younger than 5 years of age or if they had not come in due to pain. The remaining patients were called and given the option of participating in the survey. It was found that patients who had been in over a year ago often mentioned that they could not remember very well; some said that they would try to remember to the best of their ability while others declined to participate.

7.0 CONCLUSIONS

Retrospective analysis of admissions data from CHP for patients with SCD coming to the ED due to vaso-occlusive pain showed that there has been a significant decrease in rates of admissions from 2002 to the present. As the hypothesis stated, it is believed that this is a reflection on better treatment and care of patients with SCD. The implementation of individualized pain plans for each patient with SCD has likely played a major role in increasing the quality of treatment and, thus, decreasing the rates of admission at CHP. During discussions with patients regarding their current satisfaction levels, a number mentioned that the pain plans have been helpful or would rate care lower if their pain plan was not used and followed. In addition, admission rates for CHP were significantly lower than those for PHIS hospitals from 2002 to 2008 quarter 3, indicating that CHP is doing well with pain management for patients with SCD.

Overall, patients and their parents rated that their satisfaction with pain management in the ED was very good or excellent. Many patients experienced resolution of their pain by the time they left the ED. Some participants also mentioned how staff was improving in their knowledge and treatment of patients with SCD. A few mothers mentioned that as long as they called ahead to let the ED know that they were coming, they were taken back to a room immediately upon arrival and pain medications were administered. In general, it appeared that most individuals were satisfied with the care and treatment of their pain.

Now that a better method has been worked out for contacting patients it should be easier for any future work with this project to move forward at a quicker pace. In addition, any future work should be able to more easily enroll a larger number of participants. This will be helpful if and when a quality improvement program is implemented in the ED. Hopefully any follow-up measures of satisfaction will be more readily obtained. Once repeat survey results are collected, patient and parent satisfaction with pain management in the ED can be compared for before and after the implementation of a quality improvement program. If methods of improving satisfaction are found these may be developed for use in other hospitals that see patients with SCD or in ambulatory care.

From a public health perspective, SCD is associated with pain crises that causes impaired quality of life and, in many cases, frequent trips to the ED and/or admissions to the hospital. If methods of increasing patient satisfaction with pain management and reducing admissions can be determined, these methods may be implemented in other hospitals or in ambulatory care. Increasing patient satisfaction by improved care, treatment, and pain management may help to improve the quality of life for patients with SCD.

APPENDIX A

IRB APPROVAL LETTER-EXPEDITED STUDY



University of Pittsburgh
Institutional Review Board

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

Memorandum

To: BETHANNY SMITH-PACKARD, BS
From: [SUE BEERS](#), PhD, Vice Chair
Date: 12/8/2008
IRB#: [MOD08010384-03](#) / PRO08010384
Subject: Sickle Cell Patient and Parent Satisfaction with Pain Management in the Emergency Department

The University of Pittsburgh Institutional Review Board reviewed and approved the requested modifications.

Please note the following information:

Modification Approval Date: 12/4/2008
Expiration Date: 7/17/2009

Please note that it is the investigator's responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b)(5) and 21 CFR 56.108(b)]. The IRB Reference Manual (Chapter 3, Section 3.3) describes the reporting requirements for unanticipated problems which include, but are not limited to, adverse events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-383-1480.

The protocol and consent forms, along with a brief progress report must be resubmitted at least one month prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00000600 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

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

APPENDIX B

IRB APPROVAL LETTER-EXEMPT STUDY



University of Pittsburgh
Institutional Review Board

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

Memorandum

To: LAKSHMANAN KRISHNAMURTI, MD
From: SUE BEERS, PhD Vice Chair
Date: 7/22/2008
IRB#: [PRO08040184](#)
Subject: Impact of Individualized Pain Plans of the Hospitalizations of Sickle Cell Patients

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)(4)

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 C

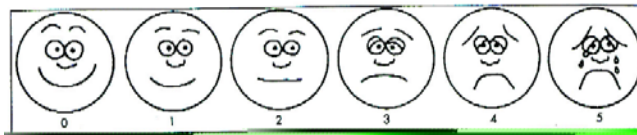
SATISFACTION SURVEY: CHILD 5-11 YEARS

CHP Pediatric ED Satisfaction Study
Child Survey (5-11)

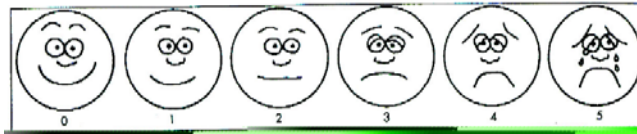
Study ID# _____

1) How would you rate the overall treatment and care you received?
Extraordinary Excellent Very Good Good Fair Poor

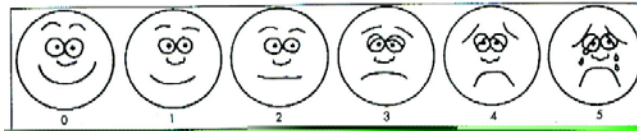
2) How nice were the doctors and nurses to you?



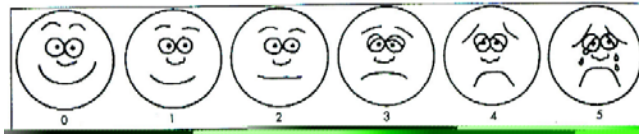
3) How much pain did you have before you came to the Emergency Department?



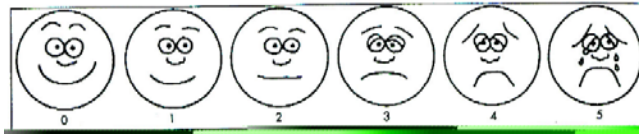
4) How much pain did you have after you came to the Emergency Department?



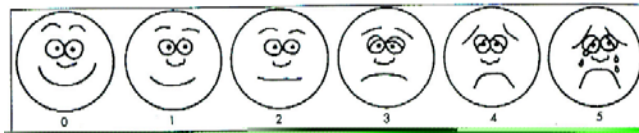
5) How much pain do you have every day?



6) How scared were you before you saw the doctor?



7) How scared are you now?



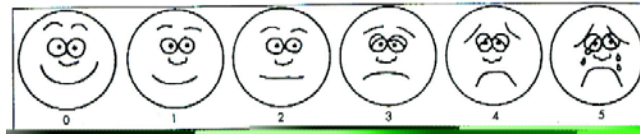
APPENDIX D

SATISFACTION SURVEY: CHILD 12-21 YEARS

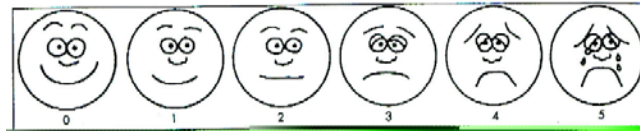
CHP Pediatric ED Satisfaction Study
Child Survey (12-21)

Study ID# _____

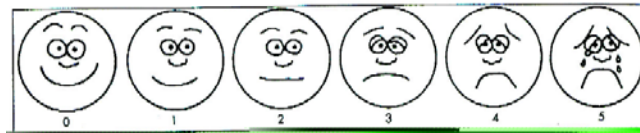
1. How would you rate the overall treatment and care you received?
Extraordinary Excellent Very Good Good Fair Poor
2. How nice were the staff and doctors to you?



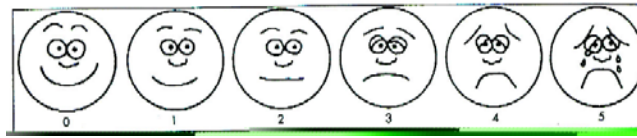
3. How much pain did you have before visiting the Emergency Department?



4. How much pain did you have after visiting the Emergency Department?



5. How much pain do you have each day?



6. How well was information given to you regarding your pain and pain management?
Extraordinary Excellent Very Good Good Fair Poor

7. Please estimate how much time you spent in the waiting room before being brought to the exam room? _____ hours _____ minutes

8. Please estimate how much time you spent in the exam room before being seen by the doctor?
_____ hours _____ minutes

9. How long did it take for you to receive medication for your pain?
_____ hours _____ minutes

10. How well was your pain managed?
Extraordinary Excellent Very Good Good Fair Poor

11. How respectful were the doctors and staff who took care of you?
Extraordinary Excellent Very Good Good Fair Poor

12. Would you recommend this emergency department to a friend?
Yes No

13. Would you return to this emergency department in the future?
Yes No

14. Any additional comments:

APPENDIX E

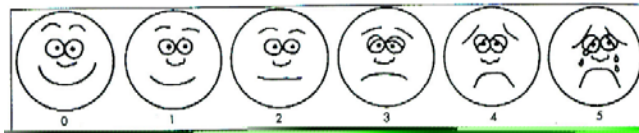
SATISFACTION SURVEY: PARENT

CHP Pediatric ED Satisfaction Study
Child Survey (12-21)

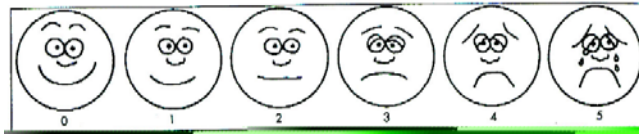
Study ID# _____

- 1) How would you rate the overall treatment and care you received?
Extraordinary Excellent Very Good Good Fair Poor
- 2) How nervous were **you** about your child's pain level?
Extraordinarily Extremely Very Moderately Mildly Not at all
Nervous Nervous Nervous Nervous Nervous Nervous

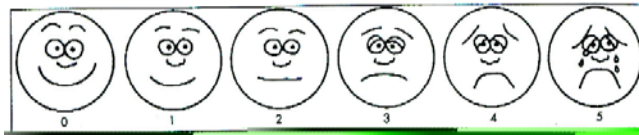
- 3) How much pain did your child have before visiting the Emergency Department?



- 4) How much pain did your child have after visiting the Emergency Department?



- 5) How much pain is your child in on a regular/daily basis?



- 6) How adequately were you informed regarding your child's pain management?

Extraordinary Excellent Very Good Good Fair Poor

7) Please estimate how much time your child spent in the waiting room before being brought to the exam room? _____ hours _____ minutes

8) Please estimate how much time your child spent in the exam room before being seen by the doctor? _____ hours _____ minutes

9) How long did it take for your child to receive medication for his/her pain?
_____ hours _____ minutes

10) How well do you feel your child's pain was managed?

Extraordinary Excellent Very Good Good Fair Poor

11) In the past year (not including your most recent visit) how many times have you brought one or more of **your children** to an emergency department for care?

0-1 times 2-3 times more than 3 times

12) Does your child have a regular primary care doctor/clinic?

Yes No

13) How respectful were the doctors that took care of your child?

Extraordinary Excellent Very Good Good Fair Poor

14) Would you recommend this emergency department to a friend?

Yes No

15) Would you return to this emergency department in the future?

Yes No

16) Any additional comments:

APPENDIX F

CHP CLINICAL EFFECTIVENESS GUIDELINES

Children's Hospital of Pittsburgh

Guidelines for Clinical Effectiveness

Sickle Cell Disease Vasocclusive Crisis ED Pain Management

Goal: Significant pain reduction in the first 1-2 hours

- Begin Pain Management Immediately
- Patients should be treated according to their individualized management plan (Refer to ED binder).
- Maintain home medications throughout ED visit.
- May hold short acting pain medications while pain is being controlled with IV pain medications.
- If no current individualized management plan is available treat according to dosing guidelines below

- Morphine 0.15 mg/kg IV bolus or
- Dilaudid 0.02 mg/kg bolus
- Ketorolac (Toradol) 0.5 mg/kg IV x 1 then: 0.5 mg/kg/dose IV q 6 hours (5day max) **NOTE: limited by FDA, if used within past 30 days use ibuprofen.**

Morphine 0.05 mg/kg q 15-30 minutes until the pain is under control or as tolerated.

When pain is under control for 45-60 minutes, give an adequate dose of an effective oral opioid analgesic (refer to individualized pain plan or equianalgesic dosing table).

If pain not in control after 4 -6 hours after admission to ED, the patient is unable to take adequate fluids orally, if patient is in severe distress or if other complications suprevene

If significant pain persists or can not take adequate fluids.

Admit to Hospital

Pain Relief maintained on oral medication for 1-2 hours

Discharge home with appropriate prescriptions and follow up appt. in Hematology Clinic in 1-2 weeks

Supportive Care

- ✓Begin IV fluid 1-1.25 times maintenance
- ✓Begin antipruritics: (Per individualized management plan or CHP formulary)
- ✓Diphenhydramine (Benadryl) 0.1-0.5 mg/kg or Hydroxyzine (Atarax) or 2-4 mg/kg/day in 6-8 doses.
- ✓Begin Antiemetic: Dose according to CHP formulary
Ondansetron (Zofran)
Proemethazine (Phenegran)
Granisetron (Kytril)

Patient Assessment

- By self report determine characteristics, location and intensity of pain q 15-30 minutes.
- Assess pain with developmentally appropriate pain scale that the patient is familiar with and understands.
- Assess causes for pain, and change from baseline in spleen, O2 Sats, and mental status.

Pain related to SCD

No

Conduct complete workup to Determine etiology of pain

Yes

Treat based on characteristics of episode.

Assess for Sickle Cell Disease related complications.

Acute chest syndrome
Stroke
Dactylitis

Splenic sequestration
Pneumococcal sepsis

CE # 210.02

Origination: 9/04

Revised:

This clinical guideline is a collaborative care plan and is not intended to construed or to serve as a standard of medical care. Rather, it is intended as a guideline to promote coordination and communication with respect to patient care and may be modified to meet individual care needs. For additional information contact the Department of Care Coordination at 412/692-7743 ©Children's Hospital of Pittsburgh, 2003

APPENDIX G

STATSTICAL ANALYSIS FOR SPECIFIC AIM I

Table 3: Admission rates for CHP compared to PHIS with proportions of patients admitted

ADMISSION RATE							
	2002	2003	2004	2005	2006	2007	2008
CHP	123	113	85	89	96	100	63
	158	174	145	162	186	180	121
	77.9%	64.9%	58.6%	54.9%	51.6%	55.6%	52.1%
PHIS	1528	1397	1374	1389	1361	1312	903
	2141	2114	2038	2060	2076	2071	1330
	71.4%	66.1%	67.4%	67.4%	65.6%	63.4%	67.9%

Table 4: Data for readmission rates from CHP and PHIS from 2002 to 2008, quarter 3

READMISSION RATE							
	2002	2003	2004	2005	2006	2007	2008
CHP	9	4	6	3	3	8	2
	123	113	85	89	96	100	63
	7.3%	3.5%	7.1%	3.4%	3.1%	8.0%	3.2%
PHIS	33	13	15	19	17	10	23
	509	279	275	278	272	262	451
	6.5%	4.7%	5.5%	6.8%	6.3%	3.8%	5.1%

Table 5: Statistical analysis of readmission data

	P-value	Interpretation at $\alpha=0.05$
Hospital	0.942	No significant difference between CHP and PHIS
Year: CHP	0.613	No significant difference over years
Year: PHIS	0.364	No significant difference over years
Interaction	0.941	No significant difference over years between hospitals

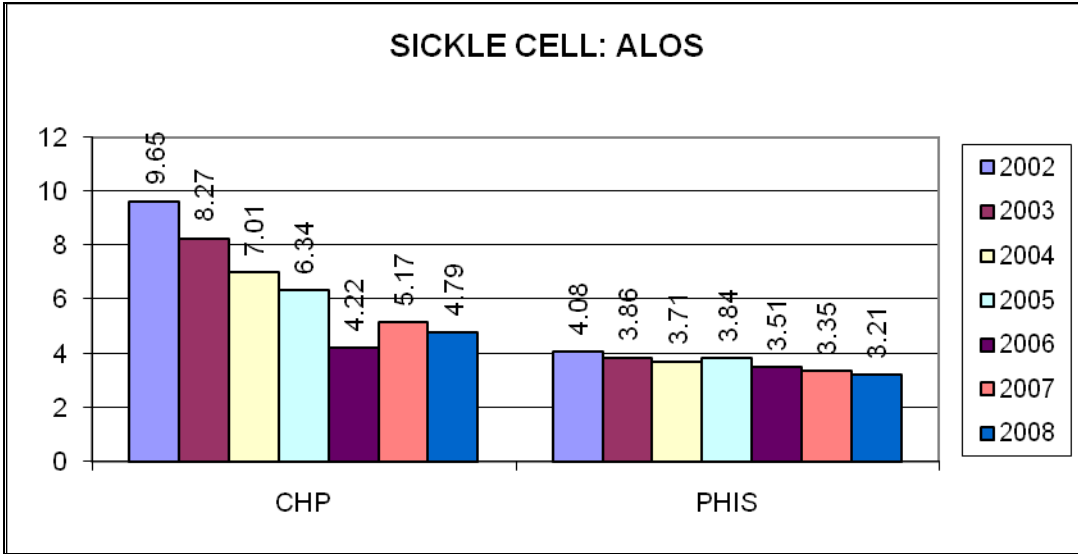


Figure 15: Average length of stay data for SCD patients from 2002 to 2008, quarter 3

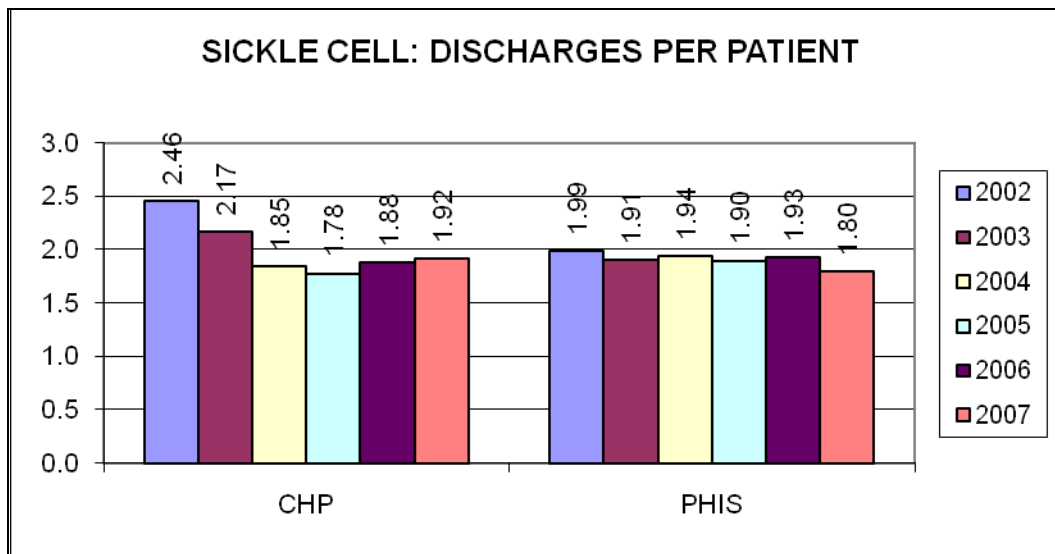


Figure 16: Discharges per patient data for SCD patients from 2002 to 2008, quarter 3

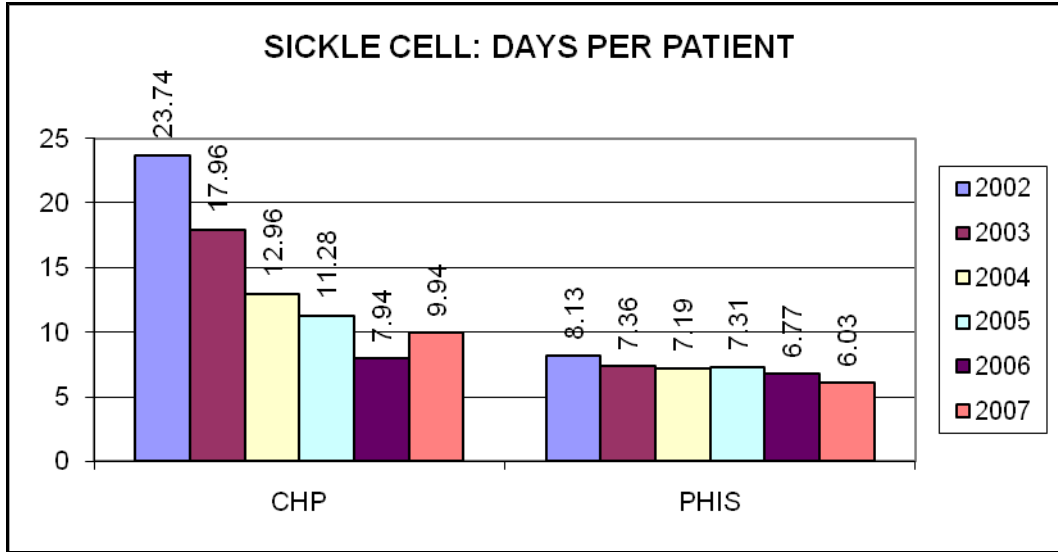


Figure 17: Days per patient data for SCD patients from 2002 to 2008, quarter 3

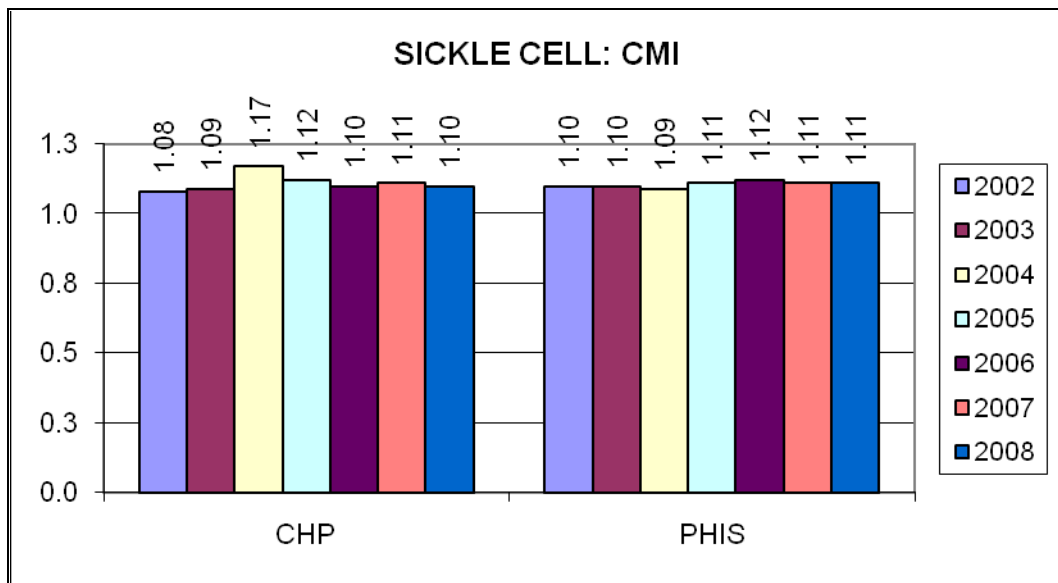


Figure 11: Case mix index (CMI) data for SCD patients from 2002 to 2008, quarter 3

APPENDIX H

STATISTICAL ANALYSIS FOR SPECIFIC AIM II

H.1 RAW DATA

Table 6: Data from ages 5-11

Question number: vertical; answers and percentages: horizontal; questions from Appendix C

Answer	0 (%)	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)	Mean
Question							
1	0 (0)	1 (14.3)	2 (28.6)	1 (14.3)	2 (28.6)	1 (14.3)	3
2	4 (57.1)	1 (14.3)	1 (14.3)	0 (0)	0 (0)	1 (14.3)	1.14
3	1 (14.3)	0 (0)	0 (0)	1 (14.3)	0 (0)	5 (71.4)	4
4	3 (42.9)	1 (14.3)	1 (14.3)	2 (28.6)	0 (0)	0 (0)	1.29
5	4 (57.1)	2 (28.6)	0 (0)	0 (0)	1 (14.3)	0 (0)	0.86
6	3 (42.9)	1 (14.3)	2 (28.6)	0 (0)	1 (14.3)	0 (0)	1.29
7	6 (85.7)	0 (0)	1 (14.3)	0 (0)	0 (0)	0 (0)	0.29

Table 7: Data from ages 12-21

Question number: vertical; answers and percentages: horizontal; questions from Appendix D

A	0 (%)	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)	Mean
Q							
1	1 (3.4)	2 (6.9)	6 (20.7)	7 (24.1)	5 (17.2)	8 (27.6)	3.28
2	22 (75.9)	1 (3.4)	4 (13.8)	2 (6.9)	0 (0)	0 (0)	0.52
3	1 (3.4)	2 (6.9)	0 (0)	1 (3.4)	6 (20.7)	18 (62.1)	4.22
4	3 (10.3)	4 (13.8)	6 (20.7)	4 (13.8)	8 (27.6)	2 (6.9)	2.59
5	10 (34.5)	5 (17.2)	3 (10.3)	8 (27.6)	1 (3.4)	0 (0)	1.48
6	1 (3.4)	2 (6.9)	6 (20.7)	7 (24.1)	9 (31.0)	4 (13.8)	3.14
7	N/A	N/A	N/A	N/A	N/A	N/A	70.74
8	N/A	N/A	N/A	N/A	N/A	N/A	53.70
9	N/A	N/A	N/A	N/A	N/A	N/A	53.34
10	2 (6.9)	4 (13.8)	7 (24.1)	4 (13.8)	9 (31.0)	2 (6.9)	2.78
11	0 (0)	1 (3.4)	2 (6.9)	5 (17.2)	10 (34.5)	11 (37.9)	3.97
12	0 (0)	27 (93.1)	1 (3.4)	N/A	N/A	N/A	1.05
13	0 (0)	27 (93.1)	1 (3.4)	N/A	N/A	N/A	1.05

Table 8: Data from parents

Question number: vertical; answers and percentages: horizontal; questions from Appendix C

A	0 (%)	1(%)	2(%)	3(%)	4(%)	5(%)	Mean
Q							
1	1 (3.2)	2 (6.5)	4 (12.8)	5 (16.1)	8 (25.8)	11 (35.5)	3.61
2	4 (12.8)	4 (12.8)	2 (6.5)	9 (29.0)	4 (12.8)	7 (22.6)	2.89
3	2 (6.5)	0 (0)	1 (3.2)	2 (6.5)	6 (19.4)	20 (64.5)	4.26
4	7 (22.6)	8 (25.8)	3 (9.7)	1 (3.2)	6 (19.4)	4 (12.8)	2.12
5	13 (41.9)	8 (25.8)	6 (19.4)	3 (9.7)	0 (0)	0 (0)	0.97
6	2 (6.5)	3 (9.7)	4 (12.8)	5 (16.1)	5 (16.1)	12 (38.7)	3.42
7	N/A	N/A	N/A	N/A	N/A	N/A	51.02
8	N/A	N/A	N/A	N/A	N/A	N/A	14.52
9	N/A	N/A	N/A	N/A	N/A	N/A	43.63
10	0 (0)	4 (12.8)	4 (12.8)	5 (16.1)	5 (16.1)	12 (38.7)	3.38
11	8 (25.8)	13 (41.9)	10 (32.3)	N/A	N/A	N/A	1.06
12	0 (0)	30 (100)	N/A	N/A	N/A	N/A	1.03
13	0 (0)	1 (3.2)	1 (3.2)	5 (16.1)	10 (32.3)	14 (45.2)	4.13
14	1 (3.2)	29 (93.5)	1 (3.2)	N/A	N/A	N/A	1
15	1 (3.2)	30 (96.8)	N/A	N/A	N/A	N/A	0.97

H.2 COMPARING BEFORE AND AFTER ED PAIN LEVELS

Table 9: Pain Level Comparisons-Children 5-11

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
outcome	Equal variances assumed	.270	.613	3.042	12	.010	2.714	.892	.770	4.658

Table 10: Pain Level Comparisons-Children 12-21

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Upper	Lower
Outcome	Equal variances assumed	2.217	.142	4.365	56	.000	1.6379	.3752	.8863	2.3896

Table 11: Pain Level Comparisons-Adult

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Upper	Lower
Outcome	Equal variances assumed	6.234	.015	5.501	58	.000	2.241	.407	1.425	3.056

H.3 DESCRIPTIVE STATISTICS FOR WAIT TIMES

Table 12: Ages 12-21 Waiting Room Times

With outliers

N	Valid	29
	Missing	0
Mean		70.74
Std. Error of Mean		50.690
Median		10.00
Mode		10
Std. Deviation		272.973
Variance		74514.083
Range		1470
Minimum		0
Maximum		1470
Percentiles	90	150.00

Without outliers

N	Valid	27
	Missing	0
Mean		13.76
Std. Error of Mean		5.522
Median		5.00
Mode		10
Std. Deviation		28.695
Variance		823.411
Range		150
Minimum		0
Maximum		150
Percentiles	90	31.40

Table 13: Ages 12-21 Exam Room Wait Times

With outliers

N	Valid	28
	Missing	1
Mean		53.70
Std. Error of Mean		16.905
Median		20.00
Mode		20
Std. Deviation		89.453
Variance		8001.766
Range		390
Minimum		0
Maximum		390
Percentiles	90	215.00

Without outliers

N	Valid	26
	Missing	0
Mean		32.83
Std. Error of Mean		8.688
Median		20.00
Mode		20
Std. Deviation		44.300
Variance		1962.499
Range		210
Minimum		0
Maximum		210
Percentiles	90	86.50

Table 14: Ages 12-21 Wait Times for Pain Medication

With outliers

N	Valid	29
	Missing	0
Mean		53.34
Std. Error of Mean		12.247
Median		25.00
Mode		10
Std. Deviation		65.953
Variance		4349.805
Range		265
Minimum		5
Maximum		270
Percentiles	90	180.00

Without outliers

N	Valid	27
	Missing	0
Mean		39.89
Std. Error of Mean		8.308
Median		25.00
Mode		10
Std. Deviation		43.172
Variance		1863.795
Range		175
Minimum		5
Maximum		180
Percentiles	90	122.00

Table 15: Parent Waiting Room Times

Without outliers

N	Valid	31
	Missing	0
Mean		51.0161
Std. Error of Mean		26.61155
Median		10.0000
Mode		.00
Std. Deviation		148.16683
Variance		21953.408
Range		660.00
Minimum		.00
Maximum		660.00
Percentiles	90	60.0000

Without outliers

N	Valid	29
	Missing	0
Mean		13.1552
Std. Error of Mean		2.94982
Median		10.0000
Mode		.00
Std. Deviation		15.88525
Variance		252.341
Range		60.00
Minimum		.00
Maximum		60.00
Percentiles	90	37.0000

Table 16: Parent Exam Room Wait Times

Without outliers

N	Valid	30
	Missing	0
Mean		14.10
Std. Error of Mean		3.171
Median		7.00
Mode		0
Std. Deviation		17.367
Variance		301.610
Range		75
Minimum		0
Maximum		75
Percentiles	90	37.00

Without outliers

N	Valid	28
	Missing	0
Mean		10.82
Std. Error of Mean		2.237
Median		6.00
Mode		0
Std. Deviation		11.835
Variance		140.078
Range		37
Minimum		0
Maximum		37
Percentiles	90	35.20

Table 17: Parent Wait Times for Pain Medication

Without outliers

N	Valid	27
	Missing	0
Mean		24.85
Std. Error of Mean		4.288
Median		20.00
Mode		60
Std. Deviation		22.283
Variance		496.516
Range		60
Minimum		0
Maximum		60
Percentiles	90	60.00

Without outliers

N	Valid	27
	Missing	0
Mean		24.85
Std. Error of Mean		4.288
Median		20.00
Mode		60
Std. Deviation		22.283
Variance		496.516
Range		60
Minimum		0
Maximum		60
Percentiles	90	60.00

H.4 OVERALL COMPARISONS

Table 18: Comparison of Overall Treatment Scores

Group 0: Adults; Group 1: Children 12-21; Group 2: Children 5-11

Outcome	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	2.971	2	1.486	.725	.488
Within Groups	131.148	64	2.049		
Total	134.119	66			

Table 19: Comparison of Information Given

Group 0: Adults; Group 1: Children 12-21

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Upper	Lower
Outcome	Equal variances assumed	3.224	.078	.730	58	.468	.281	.385	-.490	1.053

Table 20: Comparisons of Respectfulness Ratings

Group 0: Adults; Group 1: Children 12-21

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Upper	Lower
Outcome	Equal variances assumed	.016	.900	.600	58	.551	.164	.272	-.382	.709

Table 21: Comparison of "Niceness" Ratings

Group 1: Children 12-21; Group 2: Children 5-11

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Upper	Lower
Outcome	Equal variances assumed	3.455	.072	-1.249	34	.220	-.626	.501	-1.644	.392

Table 22: Comparison of Pre-ED Pain Levels

Group 1: Children 12-21; Group 2: Children 5-11

Outcome	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	.383	2	.192	.095	.910
Within Groups	129.729	64	2.027		
Total	130.112	66			

Table 23: Comparison of Post-ED Pain Levels

Group 1: Children 12-21; Group 2: Children 5-11

Outcome	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	10.305	2	5.153	1.900	.158
Within Groups	170.805	63	2.711		
Total	181.110	65			

Table 24: Comparison of Mean Daily Pain Levels

Group 1: Children 12-21; Group 2: Children 5-11

Outcome	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	4.753	2	2.376	1.535	.223
Within Groups	97.565	63	1.549		
Total	102.318	65			

Table 25: Comparison of Pain Management

Group 0: Adults; Group 1: Children 12-21

Outcome	Levene's Test for Equality of Variances	t-test for Equality of Means								
		95% Confidence Interval of the Difference		t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Upper	Lower
		F	Sig.							
Equal variances assumed	.060	.808	2.074	57	.043	.791	.381	.027	1.554	

Table 26: Comparison of Waiting Room Times

Group 0: Adults; Group 1: Children 12-21

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Upper	Lower
Waiting	Equal variances assumed	.352	.556	.098	54	.922	.604	6.141	-11.708	12.916

Table 27: Comparison of Exam Room Waits

Group 0: Adults; Group 1: Children 12-21

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Upper	Lower
Waiting	Equal variances assumed	8.644	.005	2.541	53	.014	21.689	8.535	4.570	38.808

Table 28: Comparison of Pain Meds Wait

Group 0: Adults; Group 1: Children 12-21

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Upper	Lower
Waiting	Equal variances assumed	4.005	.050	1.657	53	.103	15.210	9.180	-3.202	33.623

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