Comparison of patients with high pain scores with low-moderate pain scores in pediatric patients with sickle cell disease

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SCHOOL OF MEDICINE

Thesis

COMPARISON OF PATIENTS WITH HIGH PAIN SCORES WITH LOW-MODERATE PAIN SCORES IN PEDIATRIC PATIENTS WITH SICKLE CELL DISEASE

by

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B.A., College of the Holy Cross, 2011

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ABSTRACT

Objective: To better understand the characteristics of patients with persistently high pain scores (mean ≥ 7) as compared to those with persistently low to moderate pain scores (mean ≤ 6).

Design: This study was a retrospective chart review that compares high pain patients with sickle cell disease (SCD) and low-moderate pain patients with SCD that were admitted between 2010-2011. Each chart was reviewed for information relating to demographics, location of pain, clinical course, school progress and family structure. Any numerical measures were compared using t-tests to assess whether differences in mean values were of significance.

Results: High pain admissions showed no significant differences in BMI or hemoglobin levels at admission from low-moderate pain admissions. (p = 0.163
and \( p=0.424 \), respectively). Mean length of stay \( (p=0.048) \) and total length of stay within the two-year period \( (p=0.002) \) was significantly greater in high pain admissions. Patients in both groups had similar clinical courses, co-morbidities, long-term medications, hydroxyurea compliance, family structure and school progress.

**Discussion:** Although some factors of high pain patients differed from low pain patients, these differences do not warrant any changes in the form of care for one particular group.

**Conclusion:** Development of a method of intervention that can be administered early in order to decrease the number of pain crises would prove to be a beneficial use of resources. The use of a pain tool specific to SCD could help to standardize pain scores within this population.
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## ABBREVIATIONS

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<tr>
<td>ACS</td>
<td>Acute Chest Syndrome</td>
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<tr>
<td>BMI</td>
<td>Body Mass Index</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>ER</td>
<td>Emergency Room</td>
</tr>
<tr>
<td>FLACC</td>
<td>Face, Legs, Activity, Cry, Consolability Scale</td>
</tr>
<tr>
<td>HbA</td>
<td>Adult Hemoglobin</td>
</tr>
<tr>
<td>HbF</td>
<td>Fetal Hemoglobin</td>
</tr>
<tr>
<td>HbS</td>
<td>Sickle Hemoglobin</td>
</tr>
<tr>
<td>HMO</td>
<td>Health Maintenance Organization</td>
</tr>
<tr>
<td>HRQL</td>
<td>Health Related Quality of Life</td>
</tr>
<tr>
<td>HSCT</td>
<td>Hematopoietic Stem Cell Transplant</td>
</tr>
<tr>
<td>IEP</td>
<td>Individualized Education Plan</td>
</tr>
<tr>
<td>IV</td>
<td>Intravenous</td>
</tr>
<tr>
<td>NRS</td>
<td>Numerical Rating Scale</td>
</tr>
<tr>
<td>PCA</td>
<td>Patient controlled analgesia</td>
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<tr>
<td>RBC</td>
<td>Red blood cell</td>
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<tr>
<td>SCD</td>
<td>Sickle cell disease</td>
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<td>VOC</td>
<td>Vaso-occlusive crisis</td>
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INTRODUCTION

Sickle cell disease (SCD) is a category of disorders that affect hemoglobin, which is the protein within red blood cells (RBCs) responsible for binding and transporting oxygen to tissues within the body. It is a common genetic disorder, which affects 70,000-100,000 people within the United States, primarily blacks or African Americans (National Heart Lung and Blood Institute, 2012). The Centers for Disease Control and Prevention (CDC) estimate that SCD occurs in one out of every 500 black or African-American births, and approximately one in every 36,000 Hispanic-American births (CDC, 2011).

People with the disorder have atypical hemoglobin, titled hemoglobin S (HbS), which makes sickle-shaped red blood cells instead of healthy, disc-shaped ones. Unlike normal red blood cells, which move smoothly through capillaries and other blood vessels, these sickle-shaped red blood cells are stiffer and stick together, blocking blood vessels of the limbs and organs. The lack of blood flow that results can lead to organ damage as well as severe ischemic pain. Chronic, unpredictable pain is the most frequent complication of SCD, interfering with quality of life and requiring hospitalizations (Barakat et al, 2010). Chronic pain is defined as pain that persists for three months or more (Ballas et al, 2012). Common causes of chronic pain in patients with sickle cell disease are bone infarction, avascular necrosis of joints, back pain due to disk protrusion into vertebral bodies, leg ulcers, and chronic osteomyelitis (Ballas et al 2012).
Complications such as stroke and infections contribute to high morbidity and mortality rates in this population.

Although many patients with SCD are now surviving well into adulthood, this was not always the case. From 1910 to 1950, most patients with SCD had a lifespan of <20 years. By 1980, 50% of children survived to the age of 20. As of 2009, 85% of children with SCD survive to age 20 (Ballas et al., 2012). Newborn screening and early administration of penicillin prophylaxis may have contributed to this jump in life expectancy. Platt et al. (1994) reported that the peak incidence of death within children with SCD occurs between the ages of one and three and can be attributed primarily to pneumococcal sepsis. Deaths that occur in older aged patients are caused by a multitude of causes including acute chest syndrome and organ-system failure (Platt et al., 1994).

Hemoglobin

Hemoglobin has a quaternary structure, which consists of four globular protein subunits held together by a combination of weak forces. Each subunit of hemoglobin is made of a protein chain closely connected to a non-protein heme group. Hemoglobin’s unique structure facilitates cooperative binding, which allows for efficient oxygen and carbon dioxide transport. In normal adults, the most common form of hemoglobin is hemoglobin A (HbA), which has two alpha subunits consisting of 141 amino acid residues and two beta subunits made of 146 amino acid residues. The typical expression of the Hemoglobin beta chain gene (HBB) results in the creation of the beta globin. One of many possible
mutations in the HBB gene leads to the formation of HbS. The hemoglobin of patients with SCD contains HbS subunits instead of the normal beta globin subunits, though the alpha subunits remain unchanged. HbS differs from beta globin by one amino acid: valine replaces glutamic acid at position six in the amino acid chain. The deoxygenated form of HbS has a higher tendency to sickle, thus a decrease in oxygen in the blood can have dangerous effects. For this reason, spending time at high altitudes and airplane travel pose risks to people with SCD.

Sickle cell disease is an autosomal recessive disease, meaning that both copies of the gene in each cell have to contain mutations in order for a person to have the disease and exhibit symptoms. These patients have HbSS, the type of sickle cell disease that is commonly referred to as sickle cell anemia. If only one beta chain is replaced by HbS, the person has the sickle cell trait and is considered a carrier. The CDC estimates that approximately one in 12 African Americans possess the sickle cell trait (CDC, 2012). Carriers are often unaware of their status since they do not exhibit symptoms. The sickle cell trait is beneficial to some since it partially protects against malaria. For this reason, people with the sickle cell trait are more likely to survive in populations where malaria is endemic. When these people go on to have offspring, they pass on the sickle cell trait.

The severity of sickle cell disease varies according to the genotype and phenotype. In addition to HbSS, other common forms of sickle cell include HbSC
and HbS beta thalassemia (CDC, 2011). People that have HbSC have one copy of the sickle cell gene, which accounts for the “S” and have one copy of abnormal hemoglobin called “hemoglobin C.” Hemoglobin C results from a substitution of a lysine in place of a glutamic acid amino acid in the sixth position of the HBB gene. This mutated hemoglobin also reduces the normal flexibility of RBCs, contributing to the complications of SCD. People with HbS beta thalassemia inherit one copy of the sickle gene “S” from one parent and inherit a gene for beta thalassemia from the other parent. Beta thalassemia is a type of thalassemia that results from mutations in the HBB gene. It is inherited in an autosomal recessive fashion. Beta thalassemia is characterized as either thalassemia major or thalassemia intermedia, according to the severity of the symptoms. Thalassemia major is more severe and patients often present with symptoms earlier in life than people with thalassemia intermedia (National Institutes of Health, 2013). There are also different forms of the mutation that cause beta thalassemia, but they are not a direct indicator of the severity of symptoms. Beta-zero thalassemia occurs when there is no beta globin produced at all. People with beta-plus thalassemia are able to make beta globin, but only in limited amounts. All forms of sickle cell result in impaired hemoglobin and RBCs with less flexibility, increasing the chances for vaso-occlusive crises and resultant pain.
Sickle Cell Pathogenesis

RBCs are formed within the bone marrow and circulate through the blood vessels of the body for approximately 120 days. Once they have reached their peak, the spleen is responsible for removing them. All RBCs enter the splenic cords, which act as a filter, only allowing those of acceptable size, shape and elasticity to pass. Unacceptable RBCs are removed from the circulation and phagocytized by macrophages. Iron within the RBC is extracted and recycled to the bone marrow. Because the RBCs of patients with sickle cell disease are stiffer and crescent shaped, they are often removed from circulation prematurely, shortening their lifespan to 10 to 20 days. The destruction or rupture of RBCs is termed hemolysis. The shortage of circulating RBCs decreases the availability of oxygen to the tissues of the body. The condition is known as anemia and may lead to fatigue, shortness of breath, chest pain, dizziness, headache and cognitive problems (Mayo Foundation for Medical Education and Research, 2011). Due to the spleen’s role as a filter of RBCs, it is commonly one of the first organs negatively affected by sickle cell disease. Often, the spleen is enlarged during the first decade of life but it atrophies with age and its blood supply becomes repeatedly occluded, eventually leading to autosplenectomy in many patients with SCD (Al-Salem, 2011). Without a functioning spleen, patients with SCD are at a greater risk for contracting infections. Additional factors such as abnormalities of opsonization, antibody protection, the alternate complement
pathway, leukocyte functions and cell-mediated immunity also increase the susceptibility of patients with SCD to infections (Ahmed, 2011).

When a person with SCD experiences a vaso-occlusive crisis (VOC), the severe pain that results often requires inpatient management as well as the administration of opioids. Many studies support the idea that a VOC can be broken into phases (Beyer et al., 1999, Jacob et al., 2005) Jacob et al (2005) named the four phases: prodromal, initial, established, and resolving. The prodromal phase results in aches, numbness and paresthesias, lasting for three days and occurring pre-crisis. The second phase is the initial, evolving and infarctive phase where the pain gradually increases from aches to maximum intensity pain. Phase three is the established phase, which lasts approximately four to five days and consists of steady and severe pain. The fourth phase is resolving post-crisis which usually lasts one to two days and involves a gradual decrease in the intensity of pain. Ballas et al (2012) found that patients with acute painful crises typically receive treatment approximately two to three days after the start of the early prodromal signs. They stressed the importance of patients with SCD receiving care earlier in the process of the VOC, in order to prevent the tissue damage that occurs during the prodromal phase.

Acute chest syndrome (ACS) is the result of a VOC that blocks the pulmonary vasculature and causes a new pulmonary infiltrate on x-ray. The resulting symptoms include: “fever, cough, tachypnea, chest pain and shortness of breath” (Danielson, 2002). ACS is the second most common reason for
hospitalization in patients with sickle cell disease (Vichinsky et al., 1997). ACS progresses rapidly and must be treated immediately with blood gas monitoring, oxygen therapy, pain management to avoid splinting, the use of antibiotics and occasionally, exchange blood transfusions (Ahmed, 2011). Reagen et al. (2011) reported that ACS is responsible for up to 25% of sickle-related deaths. They also concluded that nearly half of the deaths due to ACS occur in children below the age of 20.

**Treatment**

Current treatments for SCD include the use of hydroxyurea, a cytotoxic and cytoreductive antimetabolite that inhibits ribonucleotide reductase and thus inhibits DNA synthesis (Aliyu et al., 2006). Treatment with hydroxyurea increases the production of fetal hemoglobin (HbF) while decreasing the production of HbS. Fetal hemoglobin is produced in the fetus during the last seven months of gestation and continues until approximately six months after birth, when the switch to HbA occurs. HbF has a stronger affinity for oxygen than HbS and HbA. Increasing the production of HbF in a patient with SCD can help increase oxygenation of peripheral tissues and lessen the adverse effects caused by HbS. Platt et al. (1994) concluded that the level of HbF shows a strong correlation with survival. They found that children with higher levels of HbF were more likely to survive into adulthood than those with lower levels of HbF. McGrann et al. (2011) found that hydroxyurea improves survival across SCD phenotypes; the survival
rate of patients with SCD taking hydroxyurea is compared to those who are not taking hydroxyurea and the results are illustrated in figure 1.

**Figure 1: Increased survival attributed to hydroxyurea.** Patients with SCD taking hydroxyurea had a 10 year overall survival rate of 100% while those patients not taking hydroxyurea had 10% chance at 10 year survival (p<0.01). Figure taken from McGann, 2011.
In addition to increasing the production of fetal hemoglobin, hydroxyurea also reduces the production of neutrophils and reticulocytes by bone marrow. A high white blood cell count has been shown to increase morbidity and mortality in the SCD patient population; therefore it is beneficial to decrease the number of circulating white blood cells (Ware, 2010). The multiple positive effects of hydroxyurea can be seen in figure 2. Due to its effectiveness at increasing the production of fetal hemoglobin, hematologists prescribe hydroxyurea to many patients with SCD. The regimen for hydroxyurea often requires that patients take different doses throughout the week in order to be most beneficial. Compliance issues can result in an increased chance of a pain crisis and thus a hospitalization.

Because the use of hydroxyurea can cause oral ulcers, hair loss, abdominal pain and melanonychia, patients are monitored for side effects during outpatient clinic visits. While some patients take hydroxyurea, others manage pain without it and rely on the use of pain medications such as morphine and oxycodone.
Because many patients with SCD are forced to live without a spleen, risk of infection is markedly increased in this population. Today, there are three measures that are used in order to diminish the risk of serious infection: penicillin prophylaxis, immunization against pneumococcal infection as well as the administration of folate, in the form of folic acid (Aliyu et al., 2006). Neonates are screened in the United States for SCD; if a baby tests positive, the standard of care is to treat with penicillin prophylaxis.

Blood transfusions are also a common method for management of SCD. Replacing sickled RBCs with healthy ones can increase the carrying capacity for
oxygen and lead to improvement of conditions associated with anemia. Acute simple transfusions are most appropriate for patients experiencing symptomatic anemia, aplastic crisis, splenic or hepatic sequestration, ACS, or acute failure of multiple organs with severe anemia, as well as preparation of people with SCD for surgery (Aliyu et al., 2006). Some of the risks associated with transfusions include: contracting a transfusion-transmitted infection, development of unexpected RBC alloantibodies and autoimmune anemia after RBC alloimmunization (Danielson, 2002). For patients with SCD, the benefits outweigh the risks and many patients with SCD receive regularly scheduled transfusions in an outpatient setting.

The only known cure for SCD is allogeneic hematopoietic stem cell transplant (HSCT), yet as Roth et al. (2012) explain, it is not used in many patients due to the significant risks associated with the procedure. Risks include: graft rejection, infection during transplantation, immunosuppression, graft versus host disease and death. For this reason, HSCT is only considered for those patients with the most severe cases of SCD, those that are not responding to other forms of treatment.

Because a VOC can begin suddenly and progress rapidly, identifying the symptoms early can help a patient to seek the necessary help sooner. At Boston Children’s Hospital, patients and families are educated in the Hematology Clinic on self-care including how to identify and treat vaso-occlusive crises at home to prevent admissions when possible. Plans are individualized according to past
experiences with crises, allergies, and response to analgesics. Most patients take acetaminophen, non-steroidal anti-inflammatory drugs and an opioid. If the child does not respond well to the analgesics, then the child is brought to an emergency room (ER) for intravenous (IV) opioids. If an admission is required, at this pediatric tertiary medical center, patients are usually admitted to the general pediatrics floor from the ER and IV opioids by patient-controlled analgesia (PCA) in bolus and continuous forms are initiated. Once pain is managed, the patient is discharged with oral pain medications. During admissions, nurses reinforce this education.

**Quality of Life**

Chronic and intermittent pain impacts the quality of life for a child. Health-related quality of life (HRQL) is a tool that is used to assess a patient’s beliefs about how his health or medical treatments are affecting his ability to function and his overall well being (Panepinto, 2012). Figure 3 shows the HRQL of children with sickle cell disease on a spectrum that includes healthy children and those with other chronic diseases (Panepinto, 2012).
Progress in school can serve as an indication of how SCD is affecting a child. Information about school progress is collected during hospital admissions or during regularly scheduled outpatient hematology visits. SCD can cause significant problems in school because children are often forced to miss school days due to pain or subsequent hospitalizations. An IEP is an individualized educational plan, which intends to specialize an education program for those children with special needs or disabilities. A 504 plan stems from section 504 of the Rehabilitation Act and much like an IEP, its purpose is to make a specialized plan for disabled children to perform to their highest ability in school.
Current Research

Ballas and Lusardi (2005) studied the patterns of hospital admissions and reasons for readmission in adult patients with SCD. They found that approximately 95% of the 1540 admissions of 136 patients were due to acute painful crises. Additionally, the intensity of pain scores decreased appreciably within the first 4 days after admission from an average of 8.7 ± 1.17 to 7.5 ± 1.00 (P < 0.001) as measured on a pain assessment tool from 0-10. However, pain scores remained at a mean score of 7.4/10 until discharge (Ballas et al 2005).

Zempsky et al (2008) performed a retrospective chart review of the outpatient clinic, emergency department and inpatient records for patients with SCD that were admitted for a VOC within a 2-year period. They compared patients with an extended stay (≥ 5 days) to those with a shorter stay (< 5 days) with respect to a variety of factors including pain scores and opioid use (measured in morphine equivalents). Pain scores persisted in the moderate to severe range (≥ 5) in many patients despite administration of opioids that fell within the guidelines outlined by the American Pain Society (0.1-0.15mg/kg every 2-4hrs). One suggestion for the results was central sensitization due to chronic, severe pain, which may alter a child’s perception of pain.

Solodiuk et al (2013) performed a retrospective analysis of all pain intensity scores collected from 33,000 inpatient admissions at Boston Children’s Hospital over a two-year period. From nearly one million pain scores, the mean (1.4 in 2010 and 1.34 in 2011) and median (0 in 2010 and 2011) pain intensity
scores were low overall. There were four identifiable groups that had persistently high pain scores (mean ≥ 7). Patients with sickle cell vaso-occlusive episodes were one of the four categories with high pain scores (Solodiuk et al, 2013).

Due to the widespread nature of SCD, health care costs associated with inpatient admissions remain high. Ashley-Koch et al (2000) reported that between 1989 and 1993, there were an average of 75,000 hospitalizations per year in the United States among individuals with sickle cell disease and as of 1996, the cost of the hospitalizations had reached $475 million annually (Ashley-Koch et al., 2000). It is our hope that these comparisons of sickle cell patients with high pain scores with those that have consistently lower pain scores will give insight into how to better manage pain in children with SCD.

**SPECIFIC AIMS**

Even though patients with SCD are given opioids in addition to non-steroidal anti-inflammatory drugs, patients admitted for vaso-occlusive crises with SCD continue to exhibit high pain intensity scores. The purpose of this study is to better understand the differences between patients with high pain intensity scores as compared to those with low-moderate pain intensity scores within the sickle cell population.
The specific aims of the current study are:

1. To compare similarities and differences in patients with persistently high pain intensity scores (mean ≥7) with patients with persistently low to moderate pain scores within the sickle cell patient population at Boston Children’s Hospital.

2. To measure the relationships between persistently high pain scores and additional factors such as age, ethnicity, co-morbidities, location of pain, body mass index (BMI), hydroxyurea compliance, long-term drugs, clinical course and procedures, length of stay, and number of admissions per year. We also plan to look at the following social factors: insurance status, progress in school and family structure as well as compliance with clinic visits.

Study Design

A recent study administered by Solodiuk et al (2012) compiled pain intensity scores from all inpatients in 2010-2011 admitted at Boston Children’s Hospital. Results showed that patients with SCD were within a subgroup of one percent of the population that had persistently high pain scores (mean ≥7). These findings served as the basis for this study. Charts of patients with SCD admitted to Boston Children’s Hospital during 2010-2011 for a vaso-occlusive crisis, with documented demographic data and pain intensity scores were reviewed. The study protocol was determined to be exempt from review by the Boston Children’s Hospital Institutional Review Board because it was considered new.
research activity limited to review of health information on patients. The goal of this study was to expand our knowledge of the characteristics of patients with high pain intensity scores as well as those with low to moderate pain scores in order to focus efforts towards improving the care of patients with SCD.
METHODS

This study is a retrospective chart review comparing patient demographics and comorbidities in addition to clinical course. Patients were divided into two groups: a high pain group and a low to moderate pain group based on mean pain intensity scores as documented by the staff nurses caring for the patients during the time of the patient stay. Patient demographics (age, sex, ethnicity and race, admitting diagnosis, height and weight, admission date) were retrieved from the electronic medical records. Nurses used a variety of pain scales to document pain, including FLACC, NRS and Wong-Baker FACES pain scale. FLACC (Face, Legs, Activity, Cry and Consolability) pain assessment tool is validated for assessment of acute postoperative pain in newborns and children up to seven years old. This tool consists of 5 categories, each scored from 0-2, that when totaled results in a final score between 0 and 10 (Malviya et al., 2005). Self-reported numerical rating scale (NRS) consists of numbers along the continuum. Children ages eight and older who are able to count and have an understanding of the progression of numbers can objectively relate to a concrete number corresponding to the intensity of the pain. The Wong Baker Faces scale is self-report pain intensity scale with six cartoon faces depicting with progressive distress for children ages five and up (Hockenberry, 2009) (Solodiuk et al, 2013).
Data Collection

Data was extracted retrospectively from the electronic medical record for all patients admitted. Patients with SCD and persistently high pain scores as well as those with consistently lower pain scores were identified from this data and their charts were reviewed for patient characteristics and co-morbidities that may have contributed to their pain scores. Pain intensity scores were measured by computing the mean score during each admission while characteristics and co-morbidities of each patient were recorded qualitatively. We used notes recorded in the hospital record by the hematology department to assess whether each patient taking hydroxyurea had compliance issues. The results were analyzed using Student’s t-test in order to assess whether or not the two groups of patients have different mean values on given measures. P values are two-tailed and confidence intervals were calculated at the 95th percent level.
RESULTS

We collected information on 71 admissions for vaso-occlusive crises from 47 unique patients diagnosed with SCD within a two-year period (2010 and 2011). One patient who had 17 admissions in the two-year period was excluded from the analysis in order to avoid skewing the results. Excluding this patient, the number of admissions per patient within the two-year period ranged from one to four with a mean of 1.5. Of the 71 admissions, 27 were categorized as persistently high pain, meaning the mean value of all the pain scores documented by bedside nurses was ≥ 7. The other 44 admissions had a mean pain score that was less than seven and were categorized as persistently low-moderate pain. The 27 high pain admissions came from 16 patients. Thirty-four patients accounted for the 44 low-moderate pain admissions. Number of admissions per patient ranged from one to three in the low-moderate pain group. Three patients fell into both the high pain and low-moderate pain categories during different admissions.

![Venn diagram](image)

**Figure 4**: High pain and low-moderate pain unique patients. Three patients fell into both categories.
Patients of the high pain group and low-moderate pain group were matched for age, gender and race. Of the 47 unique patients, 21 were female (45%) and 26 were male (55%). The mean age for patients upon admission was 14 years. Race and ethnicity were self-reported by patients and or parents upon admission. Eighty-five percent of patients included in the study were black or African American-non-Hispanic, 11% were Hispanic and 4% identified as other. The mean BMI at admission was 20.38. The overall average length of stay for each admission was six days and the mean total length of stay within a two-year period was approximately eight days. The majority of patients admitted had HbSS, but many had HbSC and others had HbSbeta-thalassemia. The breakdown of unique patients by type of SCD can be seen in table 1.

Table 1: Type of sickle cell disease in each patient group. Breakdown of patients by type of SCD.

<table>
<thead>
<tr>
<th>Type of SCD</th>
<th>High Pain Patients</th>
<th>Low-Moderate Pain Patients</th>
<th>Patients with High and Low-Moderate Pain Admission</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>HbSS</td>
<td>8</td>
<td>17</td>
<td>1</td>
<td>26</td>
</tr>
<tr>
<td>HbSC</td>
<td>2</td>
<td>10</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>HBS/beta-thal</td>
<td>3</td>
<td>4</td>
<td>0</td>
<td>7</td>
</tr>
</tbody>
</table>

The most common location for pain in all patients was in the legs, followed by equal accounts of pain in the arms, chest and back. Other locations of pain included the shoulders, elbows, thighs, calves, knees, hips, sacrum, buttocks, abdomen, ribs, and head. Some patients were admitted for fever, headache, coughing, wheezing or general respiratory distress in addition to a vaso-occlusive
crisis. The majority of patient admissions reported pain in one location, but the number of locations of pain ranged from zero to six and this is illustrated in table 2. Bilateral arm or leg pain was categorized as pain in two sites. There were four types of health insurance within the patient population: Medicare, in-state Medicaid, commercial insurance from a health maintenance organization (HMO), and commercial insurance from another source. Health insurance breakdown can be seen in table 3.

**Table 2: Number of sites of pain by admission.** Admissions broken down by number of sites of pain.

<table>
<thead>
<tr>
<th>Number of sites of pain</th>
<th>Number of Admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>2</td>
<td>17</td>
</tr>
<tr>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>3</td>
</tr>
</tbody>
</table>

**Table 3: Insurance types for unique patients.** Patients broken down by insurance status.

<table>
<thead>
<tr>
<th>Type of Health Insurance</th>
<th>Number of Total Patients</th>
<th>High Pain Patients</th>
<th>Low-Moderate Pain Patients</th>
<th>Both High and Low-Moderate Pain Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>In-state Medicaid</td>
<td>18</td>
<td>6</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>Commercial HMO</td>
<td>11</td>
<td>4</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Commercial other</td>
<td>17</td>
<td>4</td>
<td>14</td>
<td>1</td>
</tr>
</tbody>
</table>
The majority of admissions (35%) occurred in the fall (n=25). Equal amounts occurred in the summer and winter (24%; n=17). The fewest admissions (17%) occurred during the spring (n=12). Operational definitions for each season are reported in appendix A.

**Co-morbidities**

Although the majority of admissions showed no co-morbidities, (n=44), 14 admissions had one co-morbidity, eight admissions had two, three admissions had three co-morbidities and two admissions had four co-morbidities. Some of the conditions listed were moyamoya, diabetes, autism, pelvic inflammatory disease, and asthma.

**Clinical Course**

Upon chart review, we found the majority of patients in both the high pain (82%) and low-moderate pain (82%) groups followed the usual clinical course. Reasons for an abnormal clinical course included transfer to the intensive care unit, admission from other hospitals, and transfusion reactions or high fevers, which lengthened the hospital stay.

**Length of Stay**

Length of stay, shown in figure 4, varied significantly between the groups, with a median length of stay per admission of seven days for high pain patients and four days for low-moderate pain patients (p=0.048). Hemoglobin levels upon admission did not vary significantly between groups, with a median value of 9.2 for high pain and 9.7 for low-moderate pain (p=0.424). These results are
illustrated in figure 5. Normal hemoglobin values for healthy children can be found in appendix B.

BMI

There was no significant difference in the mean BMIs at admission of patients in the high pain group (median =19.85) versus the low-moderate pain group (median =19.35) (p=0.163). The comparison in BMI’s can be seen in figure 6.

Figure 5: Length of Stay per Admission. Comparison of high pain and low-moderate pain patients, with respect to length of stay per admission for admissions within the two-year period.
Figure 6: Hemoglobin Level. Comparison of high pain and low-moderate pain patients, with respect to hemoglobin levels upon admission.

Figure 7: Body Mass Index. Comparison of high pain and low-moderate pain patients, with respect to body mass index at time of admission.

The total length of stay during the two-year period was significantly greater in patients who had high pain scores than those who had low-moderate pain.
scores (p=0.002). The median total length of stay for high pain patients was 11 days and for low-moderate pain patients it was six days. These results can be seen in figure 7.

![Total Length of Stay in Two-Year Period by Patient](image)

**Figure 8: Total Length of Stay in Two-year Period by Patient.** Comparison of total length of stays for two-year period between patients with high pain and low-moderate pain.

**Long-Term Medications**

Any long-term home medications that patients were taking upon admission to the hospital were recorded. Medications to alleviate pain were the most common drugs in both the high pain and low-moderate pain groups. Stool softeners and laxatives were the second most prevalent drug. Folic acid was recorded for eight high pain admissions and 24 low-moderate pain admissions. Other prevalent long-term drugs included bronchodilators, antibiotics, antihistamines, iron chelators, antacids, anti-hypertensive drugs and leukotriene receptor antagonists. Table 4 shows the distribution of long term home medications being taken during high pain admissions, low-moderate pain admissions, and total length of stay.
admissions, and total admissions overall. A list of medications that fell into each category can be found in Appendix C.

**Table 4: Long-Term Home Medications.** Long-term drugs being taken by patients during high pain admissions, low-moderate pain admissions and total admissions overall, broken down into drug type.

<table>
<thead>
<tr>
<th>Type of Medication</th>
<th>High Pain Admissions</th>
<th>Low-Moderate Pain Admissions</th>
<th>Total Admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain Medication</td>
<td>41</td>
<td>91</td>
<td>132</td>
</tr>
<tr>
<td>Stool Softener/Laxative</td>
<td>21</td>
<td>39</td>
<td>60</td>
</tr>
<tr>
<td>Folic Acid</td>
<td>8</td>
<td>24</td>
<td>32</td>
</tr>
<tr>
<td>Bronchodilator</td>
<td>4</td>
<td>20</td>
<td>24</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>3</td>
<td>19</td>
<td>22</td>
</tr>
<tr>
<td>Antihistamines</td>
<td>1</td>
<td>14</td>
<td>15</td>
</tr>
<tr>
<td>Corticosteroid</td>
<td>5</td>
<td>8</td>
<td>13</td>
</tr>
<tr>
<td>Iron Chelators</td>
<td>1</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Antacids</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Antihypertensive</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Lukotriene Receptor Antagonists</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Antiemetic</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Diuretic</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Anti-depressant</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Anti-psychotic</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

**Medical Consultations**

When pediatric patients with SCD are admitted to Boston Children’s Hospital, usually from the ER, they are admitted to the general pediatrics floor. While in the ER, consults with hematology are requested. A consult with the pain team is scheduled for any SCD patient experiencing pain due to a vaso-occlusive crisis. The difference in mean number of medical consultations during admissions for high pain admissions versus admissions for low-moderate pain
was shown to be non-significant (p=0.158). The breakdown for medical consultations in both groups of patients can be seen in table 5.

**Table 5: Consultations.** Type and number of scheduled consultations made for high pain admissions and low-moderate pain admissions.

<table>
<thead>
<tr>
<th>Consultation</th>
<th>High Pain Admissions</th>
<th>Low-Moderate Pain Admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain Team</td>
<td>24</td>
<td>32</td>
</tr>
<tr>
<td>Neurology</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>IV Team</td>
<td>11</td>
<td>16</td>
</tr>
<tr>
<td>Integrative Therapy</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>General Surgery</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Psychiatry</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Rheumatology</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Neurosurgery</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Nephrology</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Blood Bank</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Plastic Surgery</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Nutrition</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Therapeutic Apheresis</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Interventional Radiology</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Cardiology</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Pulmonology</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Allergy/Immunology</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Infectious Disease</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Endocrinology</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Orthopedics</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Otolaryngology</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total Medical Consults</td>
<td>56</td>
<td>70</td>
</tr>
</tbody>
</table>
Hydroxyurea Compliance

Hematology notes were written as documentation by exception. Of the 27 high pain admissions, 9 patients were not taking hydroxyurea at the time of admit. 18 patients were taking hydroxyurea at the time of admit and of those 18, 14 were compliant and 4 were noted to have problems with compliance. Of the 44 low-moderate pain admissions, 22 were not taking hydroxyurea at time of admit, while 22 were taking hydroxyurea. Of those on hydroxyurea, 14 were noted as compliant and 8 were noted to have poor compliance with the medication regimen. These results can be seen in figure 8.

Figure 9: Hydroxyurea Compliance. Comparison of hydroxyurea compliance in high pain admissions to low-moderate pain admissions.

School Progress

We found that two patients from the high pain group, two patients from the low-moderate pain group, and one patient admitted for both high and low-moderate pain, were currently on an IEP in school. We also found that one
patient in the low-moderate pain group was currently on a 504 plan at school. We also noted concerns about school absences were expressed frequently by the patient or the patient’s family to the hematology team. Many patients were falling behind in school due to frequently missed days of school. Some received tutoring through school, some received inpatient tutoring during hospitalizations and others received no tutoring at all.

**Family Structure**

In addition to information on schooling, we also gathered data on the family structure and living situation of each patient. We found that the majority of patients were living in single parent homes. Table 6 shows the breakdown of family living situations by patient group. One patient from the high pain group is unaccounted for because no information on family structure was recorded.

**Table 6: Living Situation for Patients.** Parent or family member living with each patient.

<table>
<thead>
<tr>
<th>Living Situation</th>
<th>High Pain Patients</th>
<th>Low-moderate Pain Patients</th>
<th>High and Low Pain Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only mother</td>
<td>7</td>
<td>18</td>
<td>3</td>
</tr>
<tr>
<td>Only father</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Both parents</td>
<td>1</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>One parent and one step-parent</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Independently Living</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Living with relatives</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
DISCUSSION

Comparison between these two groups of patients with SCD, experiencing a VOC, indicates that although differences between the groups exist, they are similar with respect to most of the factors we investigated. Our results show that sickle cell patients with high pain scores do not differ greatly from those with low-moderate pain scores with respect to hemoglobin levels or BMI at the time of admission. The median hemoglobin value was 9.2 for high pain patients and 9.7 for low-moderate pain patients. Median BMI values were 19.85 for high pain admissions and 19.35 for low-moderate pain admissions.

We gathered information on all patients with SCD admitted for a VOC between 2010 and 2011. The majority of admissions occurred in the fall. This was surprising since extremes in temperature are associated with an increased risk for vaso-occlusive crises and temperatures within this range are most often seen during the summer and winter (Bender et al., 2003). Brandow et al. (2013) conducted a study to determine whether patients with SCD had increased sensitivity to cold and heat. The compared patients with SCD to healthy matched controls and found that SCD patients felt cold and heat pain at a temperature closer to 32°C than healthy controls. They recommend additional research into the mechanism underlying this sensitivity but suggested that it may be attributed to sensitization of either central or peripheral neurons, which in turn, contributes to the development of pain. Continued patient education about the importance of
avoiding any circumstances involving extreme temperatures may be useful in reducing the number of admissions throughout the year.

A notable difference between high pain and low to moderate pain patients was length of stay of each individual admission, which was significantly higher in patients with high pain (seven days) versus low-moderate pain (four days). The total length of stay for patients with high pain (11 days) was significantly greater than patients with low-moderate pain (six days). Health care providers strive to alleviate pain in patients, and that process can require additional doses of pain medication and more time in the hospital for patients with persistently high pain scores. Further research is needed to understand the relationship between length of stay and high pain scores. Location of pain was most common in the extremities, chest and back, which have been shown to be common sources of pain in previous studies. These results are consistent with other reports in the literature that have described the pain crisis as a sudden onset of pain in the lower back or one or more joints of the extremities (Ballas et al., 2012).

One reason for extended stays of patients with high pain scores could be due to the need for medical consultations. The total number of medical consultations scheduled from the 27 high pain admissions was 56. For the 44 low-moderate pain admissions, the number of consults was 70. Overall, there were a greater average number of medical consultations made for patients with high pain than patients with low-moderate pain.
The low-moderate pain group had no consultations for psychiatry, while the high pain group had seven consultations made. Of these seven psychiatric consultations, six had no diagnosis and one had a diagnosis of generalized anxiety disorder. Carroll et al (2012) compared two groups of patients with SCD, those considered high utilizing patients, who had over four emergent care visits within 12 months to low utilizing patients. They found that with respect to low utilizers, the prevalence of psychiatric illness in family members of high utilizers was three times greater. Further research into the correlation between psychiatric health and pain in patients with SCD would serve as a valuable resource.

The presence of co-morbidities may be one cause for medical consultations. Although the majority of admissions had no co-morbidities recorded (n=44), of those patients that did have recorded co-morbidities, we found a wide variety of conditions. There were two cases of moyamoya disease in the high pain admissions and one case in the low-moderate pain admissions. One case of hemosiderosis was recorded in each group. Hemosiderosis may be a result of excess iron in the blood due to RBC hemolysis and the release of hemoglobin into the bloodstream. Two cases of asthma were found in the low pain group and history of stroke was noted in one admission from each group. Additional co-morbidities were found in isolated cases including diabetes, pelvic inflammatory disease, lupus, seizure disorder, and pancreatitis.

In both the high and low-moderate pain groups, HbSS was the most frequently found type of SCD. HbSS is also the most common form of SCD found
in the population. Sixty-two percent (n=8) of the high pain patients and 55% (n=17) of the low-moderate pain group had HbSS. In the high pain group, the second most common type of sickle cell was HbS/beta thalassemia and the least common was HbSC. For the low-moderate pain group, HbSC was more common than HbS/beta thalassemia. In those three patients that fell into both categories, there was one case of HbSS and two cases of HbSC. Although HbSS was the most common type of SCD in our patient population, it is not clear that HbSS causes more pain than either of the other two types of SCD found in this population.

Analysis of type of health insurance by admission found that the most common types of insurance within the total sample were: in-state Medicaid (38%) (n=18) and commercial insurance not provided by an HMO (36%). A recent retrospective study examined self-reported pain scores in an emergency department in order to determine which factors are associated with higher pain scores. They found a positive correlation between higher-self reported pain scores and Medicaid insurance status compared to private insurance, self-pay, other forms of insurance (Marco et al., 2013). This was not the case in our study population. Within the high pain group, 40% of patients had in-state Medicaid while 53% had commercial insurance, either from an HMO or from another source. In the low-moderate group, 39% had in-state Medicaid and 61% had some form of commercial insurance. For the three patients that fell into both
categories, two received commercial insurance from an HMO and one had commercial insurance from another source.

A previous study found that of patients admitted to the ER, those experiencing a sickle cell crisis reported the highest pain scores (Marco et al., 2013). The majority of patients in both the high and low-moderate pain groups followed the usual clinical course that begins in the ER. Staff is encouraged to insert an IV in SCD patients experiencing a VOC within 30 minutes of arrival. The patient then receives two to three doses of IV opioids and IV ketorolac. If pain is still not well controlled, the patient will receive PCA and a continuous infusion of opioids.

Marco et al. (2006) investigated the use of educational materials in the form of a brochure and a video to teach patients in the ER about the self-reported pain scales. They looked at two groups of patients, participants who used the educational material and a control group. They found that of those patients who read the brochure and watched the video, 26% of them reported a statistically significant decrease in self-reported pain scores by two or more points. Nurses at Boston Children’s Hospital use a flip chart to educate parents about pain in this population. Research into the amount of available education and the techniques of explaining the current pain tools used by the ER and the hematology clinic to assess pain in patients with SCD is warranted.

Collecting information on the use of long-term medications allowed insight into the medication routine followed by patients outside of the hospital setting.
Pain medication was the most common medicine taken at home. Medication to relieve pain is often prescribed to a patient to take while experiencing a VOC. Opioids act on the enteric nervous system and bind to the myenteric and submucosal plexuses. This causes decreased fluid secretion and sphincter dysfunction (Brock, et al., 2012). The high number of stool softeners seen in our patient population is likely due to an attempt to rectify the constipation and general gastrointestinal discomfort caused by the pain medications. Another common medication found in both groups of patients was folic acid, the synthetic form of folate, a water-soluble B vitamin found in many different foods including leafy green vegetables and citrus fruits. Folic acid helps to produce and maintain new cells, thus an adequate amount is desirable in patients with SCD.

About two thirds of the high pain admissions took hydroxyurea at home. The majority of patients on hydroxyurea were compliant (78%) (n=14). Half of the low-moderate pain admissions came from patients who were on a hydroxyurea regimen and of those, 64% were noted to be compliant (n=22). Because of the effectiveness of hydroxyurea at increasing fetal hemoglobin production, we expected that a higher percentage of patients in the high pain group would be on a hydroxyurea regimen.

The number of patients living in homes with single mothers was very high within this patient population. In both the high pain and low-moderate pain group, this was the case for 58% (n=7 for high pain and n=18 for low-moderate pain) of patients. Of the three patients who fell into both categories, the figure was 100%.
A hospitalization for a pain crisis is challenging for any family, but for those single parent families, it can be even more difficult since the parent has to split time between the child in the hospital, siblings who are living at home, work and other obligations. Continued visits from social work in the inpatient as well as the outpatient setting can provide additional support for those families with single parents. Research into the stressors of families with SCD is needed in order to guide best practice in supporting these families.

The results of our analysis showed that six patients overall of the 47 unique patients were either on an IEP or a 504 in school. Because of the small sample size, we did not expect this number to be as high as it is. Further research, into the effects of sickle cell disease on school performance are warranted.

The strength of this study is the ability to compare two groups of patients, with similar demographics, both quantitatively as well as qualitatively. In addition to assessing the length of stay and the values of hemoglobin, we were also able to use a combination of notes from the hematology team as well as the social work team to assess school progress and family structure.

One limitation of this is that it was performed at one location in the city of Boston and thus results may not be applicable to other locations. In addition, because it was a retrospective study, results rely on the accuracy of information entered into the electronic medical record. Another limitation of this study was the
small sample size. The number of admissions due to VOC varies year to year so inclusion of data from a period of time greater than two years would be beneficial.

Our results support the adoption of a validated pain assessment tool to be used specifically for patients with sickle cell disease. A pain scale that accounts for a certain amount of baseline pain, frequently seen in sickle cell patients, would prove to be helpful in better assessing the unique pain caused by a vaso-occlusive crisis. Perhaps using a tool such as this could help to better distinguish chronic pain from pain resultant from a VOC.

Jacob et al. (2012) found that the use of smartphones by patients with sickle cell disease in order to access a web-based e-diary increased communication between patients and health care providers. Making the health care provider aware of the occurrence of pain and symptoms resulted in a more timely response. Supplying each patient with a smartphone as well as employing a health care provider dedicated to responding to patients may be too costly of a solution for most, but the idea of real time communication is a promising one.
Conclusion

The results of this study show that pain continues to persist in patients with SCD, despite the administration of IV analgesics during admissions, home analgesics and the use of hydroxyurea therapy. Although there are differences noted between high pain and low to moderate pain patients, these differences are not so significant that either group should be treated differently. The development and implementation of a method of intervention that could decrease the number of pain crises for both groups of patients would serve as a beneficial use of resources.
Appendix A: Operational Definitions of Each Season.

<table>
<thead>
<tr>
<th>Season</th>
<th>Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Winter</td>
<td>December 21- March 20</td>
</tr>
<tr>
<td>Spring</td>
<td>March 21- June 21</td>
</tr>
<tr>
<td>Summer</td>
<td>June 22- September 22</td>
</tr>
<tr>
<td>Fall</td>
<td>September 23- December 20</td>
</tr>
</tbody>
</table>
Appendix B: Normal Hemoglobin Levels for Children. Table adapted from Irwin, 2001.

<table>
<thead>
<tr>
<th>Age</th>
<th>Hemoglobin Level (g/dL)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth- 6 months</td>
<td>18.5- 12.6</td>
</tr>
<tr>
<td>6 months- 2 years</td>
<td>12.0</td>
</tr>
<tr>
<td>2 years – 6 years</td>
<td>12.5</td>
</tr>
<tr>
<td>6 years to 12 years</td>
<td>13.5</td>
</tr>
<tr>
<td>12 years to 18 years: MALES</td>
<td>14.5</td>
</tr>
<tr>
<td>12 years to 18 years: FEMALES</td>
<td>14.0</td>
</tr>
</tbody>
</table>
Appendix C: Types of Medication in Each Category.

Pain Medications:
- Acetaminophen
- Ibuprofen
- Oxycodone
- Morphine
- Hydromorphone
- Methadone
- Aspirin
- Naproxen
- Gabapentin

Stool Softener and Laxatives:
Docusate-Senna
Docusate
Senna
Polyethylene Glycol

Bronchodilators:
Fluticasone-Salmeterol
Albuterol
Aerochamber

Antibiotics:
Amoxicillin
Amoxicillin-Penicillin
Penicillin
Penicillin V Potassium
Penicillin
Erythromycin
Levofloxacin

Antihistamine:
Loratidine
Diphenhydramine
Cetirizine

Corticosteroids:
Fluticasone

Iron Chelators:
Deferoxamine
Deferasirox
Antacid:
Omeprazole
Raniditine
Bismuth

Antihypertensive Drugs:
Losartan
Atenolol
Betaxolol
Verapamil
Amlodipine

Lukotriene Receptor Antagonist:
Montelukast
Zafirlukast (Accolate)

Antiemetic:
Ondansetron

Diuretic:
Amiloride

Anti-Depressants:
Amitriptyline

Anti-Psychotic:
Risperidone
REFERENCES


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Boston University School of Medicine - Boston, MA
Sept 2011- present
Pursuing a Masters of Arts in Medical Sciences

Bachelor of Arts in Spanish, pre-medical concentration
Dean’s List, First Honors (Fall 2010, Spring 2011)

Experience

Boston Children’s Hospital- Boston, MA, Graduate Student Research Intern
Sept 2012- June 2013
· Worked with pain team within the anesthesia department
· Assisted with data collection and writing for pain score study
· Conducted research on sickle cell patients

AmeriCares Headquarters- Stamford, CT, Free Clinics Intern
June 2011- Aug 2011
· Conducted research on available medical resources for the uninsured
· Interviewed directors of agencies and administered surveys to potential patients
· Composed a needs assessment report

UMASS Memorial Children’s Medical Center- Worcester, MA, Intern
Jan 2011-May 2011
· Shadowed surgeon-in chief during clinic appointments
· Observed various surgical procedures within pediatric surgery unit

AmeriCares Free Clinic- Bridgeport, CT, Patient Care Coordinator
Summers 2008, 2010
· Independent research to develop a weight loss program, “Healthy in a Hurry” for obese teens
· Contracted teens with a BMI over thirty and met to talk about healthy eating and daily exercise
· Scheduled appointments and made referrals; screened patients upon arrival
· Shadowed doctors and assisted with Spanish translation

**Medical Mission Trip-Dolores de Copan, Honduras  Aug 2010,2011**
· Set up and worked at a clinic for one week servicing patients from rural Honduras
· Served as translator for various doctors
· Assisted with physical therapy, vision screening, labs, and triage

**Community Service**

**La Cadena de Amistad- Boston, MA  Jan 2012- present**
· Volunteer as medical escort for Spanish speaking elders

**Big Brother/ Big Sister-Worcester, MA and Boston, MA  2007-present**
· Served as a mentor to an eight year old girl

**La Cruz Roja-The Red Cross in La Coruña, Spain  2009-2010**
· Volunteered with the emergency department
· On duty at sporting and public events to assist with injured spectators or participants

**Camp Amerikids-Warwick, NY  Summers 2008, 2010-2012**
· Volunteered one week as a camp counselor for children infected/affected by HIV/AIDS

**Skills**
· Fluent in Spanish
· Proficient in Microsoft Word, Excel, and Power Point