5-2-2017

# Sickle Cell Pain Management During the First 24 Hours of Inpatient Care Compared to the National Heart Lung and Blood Institute Clinical Practice Guidelines for the Emergency Department: A Quality Improvement Project

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## Abstract

Sickle Cell Pain Management During the First 24 Hours of Inpatient Care Compared to the National Heart Lung and Blood Institute Clinical Practice Guidelines for the Emergency Department: A Quality Improvement Project

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This quality improvement project addressed the clinical practice patterns for the first 24 hours of the hospitalized adult for inpatient care in comparison to the established guidelines for the emergency department treatment of sickle cell pain with the NHLBI 2002 and 2013 guidelines in a suburban teaching hospital. The analysis focused on the treatment provided which included information regarding patient assessments, utilizations for intravenous fluids, oxygen administration, the choice of pain medications including opioids, NSAIDS, and other adjuvants. A post hoc retrospective chart review was conducted with data abstraction on the current clinical practice utilized during the inpatient admission which identified deficits that will lead to the creation of a clinical dashboard for ongoing quality improvement and outcome monitoring. This process was guided by the principles of the Dartmouth Clinical Microsystem's and the 5 P's: Purpose, Patients, Professionals, Processes, and Patterns for a complete system change. The overall focus for change was intravenous fluids and rates, opioid titration for pain relief, and patient reported desired pain goals.

# Sickle Cell Pain Management During the First 24 Hours of Inpatient Care Compared to the National Heart Lung and Blood Institute Clinical Practice Guidelines for the Emergency Department: A Quality Improvement Project

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B.S.N., University of North Florida, 2001
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A Dissertation
Submitted in Partial Fulfillment of the
Requirements for the Degree of

Doctor of Nursing Practice
at the
University of Connecticut

May 2017

APPROVAL PAGE

Doctor of Nursing Practice Dissertation

Sickle Cell Pain Management During the First 24 Hours of Inpatient Care Compared to the National Heart Lung and Blood Institute Clinical Practice Guidelines for the Emergency Department: A Quality Improvement Project

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2017

**Acknowledgements**

I am thanking God, the head of my life for girding and strengthening me to complete this daunting and overwhelming task. It has been an arduous journey from the beginning. God's grace kept me, and He sent help, guidance, and encouragement from many people during this phase of my journey. This daunting task has come to fruition allowing for the next great journey. I would be remiss for failing to acknowledge those individuals that gave of themselves in helping me towards this great task.

I want to first give many thanks to my major advisor Deborah McDonald for her tireless encouragement. Dr. McDonald, when I wanted to give up so many times during this journey you continued to encourage me and remind me of the importance of this work and the impact this information would have in the lives of individuals living with sickle cell disease. With every new obstacle, you guided me, encouraged me, and pushed me which in this process turned lemons into lemonade. You've shown me the complexity of research, honed my professional writing skills, and motivated me to complete a very important project for others. Thank you for taking me under your wing and helping to mold a more insightful clinician and now researcher. Thanks to you I have a new respect, deeper understanding, and appreciation for research period. I also want to thank my associate advisors Dr. Carol Polifroni for stepping in and giving 100%. Your input helped to move this project along at a crucial time and gave added depth and additional direction. Dr. Biree Andemariam for always being available and responsive, giving this project insight and encouraging me from the onset. When I asked if you would do this you answered without hesitation and has been with me hand in hand thru this journey. I would also like to equally thank Dr. Paula McCauley and Dr.

Joan Kuhnly (Readers) for your time, support, and suggestions, your feedback helped to keep me clear, concise, and focused. I appreciate you both and your recommendations.

I would also like to acknowledge and thank all the professors and staff of the School of Nursing who gave of yourself in the classroom, on the discussion board, an encouraging word, and/or smile. The impact you have made created an opportunity to successfully write and defend a dissertation. I would also give a very special thanks to classmates for their encouragement and to those who helped to support this educational endeavor including, friends, colleagues, and my church family both in Connecticut and Texas.

Without the love and support of my family this could not have been undertaken-I am grateful you encouraged, pushed, and carried me through this very long difficult process. Thank you, mother, Elma Turner, Genois Nelson (son), GeRand Nelson (son), Dimitri Smith (son), Lakeisha Gibson (daughter) and my siblings Shevalle Kimber, Phyllis Turner, and George Turner. To the rest of my family thank you, I also love the support you have shown me. My mentor and dear friend Dr. Victoria Odesina, you will always hold a special place in my heart for encouraging me to undertake this arduous journey. It has been a struggle but well worth the fight- Thank you.

Even though I have had tremendous support for this project, any errors and/or omissions are solely my own.

## Dedication

This work is dedicated to my children Genois, GeRand, Dimitri, and my parents the late Reverend George R. Turner, Sr. and Mrs. Elma B. Turner.

This work is also dedicated to the many individuals and their families living with sickle cell disease that have allowed me to become a part of their journey. You have helped to guide my path to actively seek ways to improve pain, provide advocacy, educate the community, and hopefully these actions improved the quality of your care and added positively to your life.

This has been a shared journey of many opportunities to provide voice when yours was too weak or not being heard. Again, thank you for sharing your experiences, trusting me, and embracing me as your provider, family, and friend. I have been blessed, humbled, and deeply honored to serve you. Thank you

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# Chapter 1

## Background of the Problem

Sickle cell disease is a lifelong, genetic, hematologic disorder in which the body produces abnormally shaped erythrocytes (Telfair, 2003). Normal red blood cells or erythrocytes are traditionally bi-concave discs that move easily through the blood vessels and carry oxygen to all parts of the body (Ballas, 2005). However, “sickle cells” are hard, sticky, and tend to clump together. The cells then get stuck and literally block the flow of blood to the organs and limbs, causing pain, anemia, and organ damage (Ballas, 2010). A genetic mutation in β-globin gives rise to altered hemoglobin, the oxygen-carrying molecule, found within erythrocytes. This variation has been identified as a genetic “switch” of valine for a glutamate. This results in abnormally formed hemoglobin, which distorts the shape of red blood cells in individuals with sickle cell disease.

In the African American community, the incidence of sickle cell disease is approximately 1:400 live births. The incidence of the sickle cell trait, the carrier status, occurs in 1:12 live births, while Hemoglobin C trait occurs in 1:50, β+ thalassemia trait occurs in 1:100, β° Thalassemia trait occurs in 1:1000, and Sickle Hemoglobin C Disease occurs in 1:1250 (Whitten, 2001). In the United States, sickle cell disease affects more than 100,000 people, while globally sickle cell disease affects more than 2.5 million individuals (Ballas, 2010; Hassel, 2010; Mvundura, 2009). Sickle cell disease is common in parts of Africa, particularly Sub-Saharan Africa. Sickle cell disease is also common in Spanish-speaking countries in South America, Central America, and parts of

the Caribbean. In addition, sickle cell disease is prevalent in Saudi Arabia, India, and Mediterranean countries such as Turkey, Greece, and Italy (Smith et al., 2005; Whitten, 2001).

Because of the nature of sickle cell disease as a chronic illness, the burden of care can be tremendous on families and communities. The most common reason that persons with sickle cell disease engage medical care and acute care services is that they frequently suffer from vaso-occlusive crisis pain episodes (Adams-Graves, P., Ostric, E. J., Martin, M., Richardson, P., & Lewis, J.B., 2008). In fact, patients with sickle cell disease utilize more emergency department services than patients with other more common chronic illnesses such as diabetes, asthma, and hypertension (Ballas, 2009; Ballas & Lusardi, 2005; Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010; Moore, Charache, Terrin, Barton, & Ballas, 2000). Many researchers suggest this may be directly related to the lack of consistent care and management of adult sickle cell disease patients in both the inpatient and the outpatient settings (Aisiku et al., 2007; Ballas & Lusardi, 2005; Epstein, 2005).

Pain management for an adult in vaso-occlusive crisis includes the timely administration of adequate doses of analgesia, intravenous fluids, and adjuvant anti-inflammatory treatments that assist the patient to maintain a tolerable level of pain and to function without impairment (Frei-Jones, Baxter, Rogers, & Buchanan, 2008; Frei-Jones, Field, & DeBaun, 2009; Lopez, Flenders, Davis-Moon, Corbin, & Ballas, 2007). Guidelines specific to the management of sickle cell pain episodes have been developed to reduce provider bias based on race and gender of the patients and for facilitation of equal access to quality care during a pain episode in most care settings

including the home, primary care/out-patient, and emergency department. However, these guidelines do not extend to the in-patient setting (Benjamin et al., 1999; NHLBI, 2004; Platt et al., 2002; Rees, 2003).

**Purpose of Practice Change**

A quality improvement project to identify and enhance key clinical practices in a vaso occlusive crisis of an adult with sickle cell disease was conducted. The pain episode treatments during the initial 24 hour period of hospitalization were compared to the NHLBI emergency department guidelines. The literature currently does not include data that compares inpatient management of adults with acute SCD pain during the first, critical 24 hours with the NHLBI emergency department management guidelines.

This project compared inpatient clinical practice patterns in a single setting to the most current (2002) NHLBI emergency department guidelines. Clinical practice pattern deficits were identified in order to test and refine dashboard measures: patient assessments, utilization of intravenous fluids, oxygen administration, and choice of pain medications including opioids, NSAIDS, and other adjuvants to be tracked over time. The clinical dashboard is a provider tool to monitor patient care. The clinical dashboard was the measure to monitor high quality care and guide clinical practice patterns based on these identified clinical practice deficits. The dashboard enabled the clinical practice changes required to correct these deficits to remain easily identified and correctable with systematic monitoring over time. The measures identified were used to recommend microsystems change using the Dartmouth model.

The following questions were addressed for each unique individual hospital admission during the preceding one year:

1. What are the differences between clinical management approaches within the first 24 hours of inpatient admission at the facility and the national NHLBI standards'?
2. What are the quality improvement outcomes that need to be tracked over time to evaluate the closure of identified practice gaps?

**Significance of Project**

The mental and physical challenges of acute and chronic pain coupled with other psychosocial issues can become overwhelming and difficult to navigate for patients and families (Aisiku et al., 2007; Bediako, Lavender, & Yasin, 2007; Jenerette & Murdaugh, 2008). Likewise, the uniqueness, complexity, and variability of sickle cell pain in adults with SCD make its management very challenging for providers. Pain management for an adult in vaso-occlusive crisis includes the timely administration of adequate doses of analgesia, intravenous fluids, and adjuvant treatments that assist the patient to maintain a tolerable level of pain and to function without impairment (Frei-Jones, Baxter, Rogers, & Buchanan, 2008; Frei-Jones, Field, & DeBaun, 2009; Lopez, Flenders, Davis-Moon, Corbin, & Ballas, 2007). One of the identified barriers to quality pain management for adults listed in the American Pain Foundation Revised Pain Care Bill of Rights as cited by the *Journal of Pain and Palliative Care Pharmacotherapy* (Anonymous, 2004) is that care providers often mistrust the patients and characterize patients' behavior as "drug-seeking." Similar barriers have been documented in adults with SCD (Ballas, 2010). According to Ballas and Lusardi (2005), judgmental providers – nurses and medical

staff – were more likely to provide suboptimal pain management. Yet, for individuals with sickle cell disease, the management of acute pain episodes that require hospital treatment is an important aspect of their care. It is the responsibility of providers to remove the labels of “drug-seeking” and “drug-abusers” and provide non-judgmental care for sickle cell disease patients (Ballas & Lusardi, 2005, Maxwell, 1999).

Guidelines specific to the management of sickle cell pain episodes have been developed to facilitate equal access to quality care during a pain episode in all care settings including the home, primary care/out-patient, emergency department, with the exception of in-patient (Benjamin et al., 1999; NHLBI, 2002; Platt et al., 2002; Rees, 2003 ). Limited guidelines are widely available for the management of sickle cell disease acute care. Rees (2003) emphasizes the utilization of identification cards with baseline information of individualized care for the cardholder, expressing the need for urgency and expediency in care management for adults and children. The National Institute for Health and Clinical Excellence, 2012 (NICE) has a similar individualized patient care focus with the difference being based on patient reporting, which should include: frequent assessments, consideration of sickle cell complications while managing pain, and following the local protocols for management for the individual across the lifespan. The existing NHLBI (2002) guideline for pain management in the emergency department for hospitalized adults with sickle cell disease has specific recommendations for treatment shown in Table 1.

Table 1. *NHLBI SCD Vaso-Occlusive Management Recommendations*

<table>
<tr><td colspan="3">Assessment and Reassessments: for the individual’s pain episode</td></tr>
<tr><td>Initial rapid assessment- of acute painful episode including pain intensity, prompt treatment and relief.</td><td>Reassessments – frequent reassessments every 15-30 minutes after the administration of pain medications for pain intensity, relief, mood, and sedation level.</td><td>Response to therapy – reported reduction in pain intensity of at least 50-60% from the upper end of pain score.</td></tr>
<tr><td colspan="3">Intravenous hydration:</td></tr>
<tr><td>Initial fluid should be 5% dextrose + half-normal saline.</td><td>Add 20 mEq KCl/L adjusted for serum chemistries.</td><td>Total fluids not to exceed 1.5 times maintenance dose.</td></tr>
<tr><td colspan="3">Administration of Oxygen: 2 liters via nasal cannula for patients with pulse oximetry of 92-95%</td></tr>
<tr><td colspan="3">Administration of Opioids and Adjuvants: Short-acting opioid agonists</td></tr>
<tr><td colspan="2">For adults with ≤ 50 kg body weight:<br><br>Morphine: 0.1-0.15 mg/kg every 2-4 hours (parenteral); 0.30 mg/kg every 3-4 hours (oral).<br><br>Hydromorphone: 0.015-0.020 mg/kg every 3-4 hours (parenteral); 0.06-0.08 mg/kg every 3-4 hours (oral).<br><br>*Meperidine: not recommended</td><td>For adults with ≥ 50 kg body weight:<br><br>Morphine: 5-10 mg every 2-4 hours (parenteral);<br>10-30 mg every 3-4 hours (oral).<br><br>Hydromorphone: 1.5 mg every 3-4 hours (parenteral); 7.5 mg every 3-4 hours (oral).<br><br>Oxymorphone: 1.0-1.5 mg every 6hours (parenteral) or 0.5 mg IV and cautiously titrate upward. *Meperidine: not recommended</td></tr>
<tr><td colspan="3">Other routes of administration: Subcutaneous (for the individual with poor or no venous access to prevent delays in treatment) and patient controlled analgesia (PCA).</td></tr>
<tr><td colspan="3">Non-steroidal anti-inflammatory drugs (NSAIDS):<br><br>Ketorolac (parenteral) for inadequate analgesia after optimal titration or when the side effects of opioids are problematic (maximum use of 5 days/month).</td></tr>
</table>

*Note. NHLBI Guidelines 2002*

There have been a limited number of studies which demonstrated that implementing clinical practice guidelines for the inpatient adult with sickle cell disease could provide consistent quality care with positive patient outcomes (Adams-Graves, Lamar, Johnson, & Corley, 2008; Ballas & Lusardi, 2005; Givens et al., 2007). Adams-Graves (2008) created a disease-specific, inpatient hospital care unit within the confines of an academic teaching hospital, with the primary purpose of caring for adult sickle cell patients. This disease-specific unit was intended to improve care management of adults experiencing vaso-occlusive pain episodes or other complications of sickle cell disease. Ballas and Lusardi (2005) developed disease specific treatment guidelines to provide optimal management patients with SCD in the hospital setting. Increased utilization of the existing guidelines or their adaptation would be one approach to assure equal access to the evidence-based treatment guidelines and improve care for this patient population given the pain episodes that are endured. Repeated pain episodes' prompt adults with SCD to be hospitalized multiple times. An adult inpatient hospitalized with vaso-occlusive crisis episode pain stays for an average of 6.5 days (Adams-Graves, 2008; Epstein et al 2006). Utilization of these clinical practice guidelines could potentially reduce the number of hospital days, decrease the cost of care, increase patient satisfaction, improve quality of life, and improve overall pain management (Adams-Graves et al., 2008; Frei-Jones et al., 2009).

**Theoretical Framework**

Kolcaba (2001) stated comfort has many aspects and domains. The nurse's goal is to create and maintain a holistic environment and atmosphere in which patients can recover and maintain optimal health. Comfort for many is more than just the absence of

pain. It is the maintenance of a nurturing, caring, and stable environment that allows the patient to have access to the medications and treatments that will alleviate pain and other complications in a manner that allows them to flourish in their comfort which was used as the theoretical framework for this quality improvement project.

The Dartmouth Clinical Microsystem (2005), a systematic approach for quality improvement, was used as the methodology to guide the project. The Dartmouth Clinical Microsystem (2005) aided in the assessment of the current clinical practice patterns in comparison to the NHLBI guidelines: via *post-hoc* medical record review, determining themes from the data abstraction, global aim, and/or specific aims for improvement as determined by the data analysis, and the need to change ideas with education for the staff, patient, and/or other stakeholders to implement quality improvement initiatives. The use of the Dartmouth Clinical Microsystem helped to assess the current state of the clinical practice patterns by utilizing the following characteristics known as the “5P’s”:

1. Purpose- set goals for the program to specifically improve the quality of care and reduce pain as expeditiously as possible for the hospitalized adult experiencing a vaso-occlusive pain event.
2. Patients- utilize patient characteristics and demographics to determine how best to involve the patients in the quality improvement (QI) process.
3. Professionals- determine team member roles, work hours, satisfaction, and then optimize roles for improving the quality of care for patients hospitalized with vaso-occlusive pain.

4. Processes-Identify the daily nursing processes for the care of these patients during the initial 24 hours of hospitalization? What are the usual processes?
5. Patterns- Evaluate potential daily interruptions? What are the similar concerns or questions of the patients? When does the team meet? What are possible outcomes? These are key components that will be addressed with the creation of the dashboard for monitoring this QI project.

**Summary of Chapter**

Sickle cell disease a genetic hematologic red blood cell disorder causes severe pain and organ damage that leads to frequent episodic pain requiring medical intervention (Ballas & Lusardi, 2010 & Odesina et al., 2010). Considered a rare disease in the United States, globally approximately 2.5 million more people are affected with the disorder (Ballas, 2010; Hassel, 2010; Mvundura, 2009). This chronic disorder has the highest utilization of services, as measured against other chronic disorders such as diabetes and hypertension (Ballas, 2009; Ballas & Lusardi, 2005; Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010; Moore, Charache, Terrin, Barton, & Ballas, 2000).

One of the most important aspects and ultimate goals of pain management is to adequately relieve pain, or alleviate pain to a tolerable level (Adams-Graves et al., 2008; Ballas & Lusardi, 2010; Brousseau et al., 2010; Frei-Jones et al., 2008; NHLBI, 2002; Odesina et al., 2010; Smith et al., 2005 ). Determining clinical practice pattern deficits to test and refine dashboard measures (patient assessments, utilization of intravenous fluids, oxygen administration, and choice of pain medications including

opioids, NSAIDS, and other adjuvants) to be tracked over time provided the foundation for refining clinical practice patterns and the overall improvement of pain and comfort for patients.

This quality improvement project was focused on evaluating the clinical practices to improve inpatient pain management using the Dartmouth Clinical Microsystem. Many researchers have suggested treatment guidelines would aid in the management of the hospitalized adult. A methodical literature review was conducted to guide the clinical practice pattern data abstraction for pertinent information to guide quality improvement recommendations and the clinical dashboard for monitoring ongoing clinical practice improvements.

# Chapter 2

## Literature Review

### Introduction

This quality improvement project helped to identify current clinical practice patterns and determined what and where practice changes were needed to foster evidence-based practice for improved management of sickle cell pain in the inpatient setting during the initial 24 hours of hospitalization. This review included a comprehensive search of Medline, Cinahl, AHRQ Guidelines, DynaMed, Google Scholar, and the Cochrane Library.

The keywords used to search the databases included *sickle cell*, *pain management*, *protocols*, *pain crisis*, *sickle cell disease clinical practice guidelines*, *evidence-based clinical practice guidelines for the treatment/management of sickle cell pain*, *sickle cell disease pain management*, *care of the adult with sickle cell disease*, *pain management for adults with sickle cell disease*, *sickle cell disease protocols*, *pain crisis guidelines for sickle cell disease, sickle cell treatments, quality improvement for sickle cell disease management, and sickle cell practice patterns*. Of the 85 listings that were retrieved from published studies during the time span of 1985-2015, 21 studies met the inclusion criteria. Criteria for a study to be included as part of this systematic review were: the study needed to focus on persons with confirmed diagnoses of sickle cell disease; and/or the management or treatment of persons in vaso-occlusive crisis; and/or the study had to discuss the utilization of information regarding hospital or

emergency department use, self-care and management of sickle cell disease, and access to treatment for management of sickle cell vaso-occlusive episodes.

Of the published literature, only one of the studies, a randomized controlled trial, met the inclusion criteria as the gold standard for research. The number of peer reviewed, randomized controlled, or quantitative studies available in the literature is limited to one for adults. This limitation suggests the need for continuing research that may improve the quality of care for individuals seeking treatment for vaso-occlusive pain episodes.

A methodical review of the literature was conducted to determine the scope of literature available regarding clinical practice patterns for the hospitalized adult with sickle cell disease experiencing a vaso-occlusive crisis pain episode. No research currently exits that compares inpatient management of adults with acute SCD pain during the first, critical 24 hours with the NHLBI emergency department management guidelines.

Research was limited regarding clinical practice guidelines for the care of the adult hospitalized and experiencing a vaso-occlusive crisis pain episode. The following review includes several aspects of care: psychosocial issues of SCD, mortality/morbidity of SCD, provider knowledge, clinical practice patterns, utilization of services, financial burden of care, average length of stay (ALOS), and clinical practice guidelines and protocols. This information was utilized for determining the current clinical practice patterns for the hospitalized adult experiencing a sickle cell vaso-occlusive crisis pain episode.

## Pathophysiology of Vaso-Occlusive Crisis Pain Episodes

The latest evidence available suggests that sickle cell vaso-occlusive crisis pain episodes are the culmination of physiological processes that occur concurrently within the body and cause the individual to suffer varying degrees of pain (Ballas, 2010; Newcombe, 2002). With the occurrence of low oxygen, the red blood cells undergo polymerization, which causes the cells to become rigid and deforms the cell membrane. The polymerization has a domino effect, initiating a myriad of processes characterized by an inflammatory process, which in turn creates a complex sickling deluge. This deluge includes the dehydration of the red blood cells, which in turn creates an irreversible sickling of the red blood cells, hemolysis which leads to anemia, and vasoconstriction caused by nitric oxide depletion. The outcome from these cyclical events is vaso-occlusion, which causes pain from the underlying ischemia related to the occlusions and also causes a depletion of oxygen from the tissues. This cascade of events can then lead to organ damage (Claster, 2003; Field, Knight-Perry, & Debaun, 2009; Platt, Eckman, Beasley, & Miller, 2002).

There are many contributing factors that may trigger a vaso-occlusive crisis pain episode, which include the following: physical and emotional stress, extreme temperature changes, infections, and dehydration. However, some vaso-occlusive crisis pain episodes may have no trigger or contributing factors: for example, some episodes occur during sleep, yet physical and emotional stress, extreme temperature changes, infections, and dehydration can also trigger vaso-occlusion while the individual is asleep (Aisiku et al., 2007; Benjamin, Swinson, & Nagel, 2000; Dunlop, 2006; Givens, Rutherford, Joshi, & Delaney, 2007). Vaso-occlusive crisis pain episodes can occur any

time of the day or night and are unpredictable by the potential for sudden onset and varying degrees of pain intensity as experienced by the individual. This is not to say that all episodes are spontaneous. There are some instances in which the onset of a pain crisis can be predicted by some individuals under certain circumstances (Newcombe, 2002; Smith et al., 2008; Smith et al., 2005).

Ballas (1995) indicated that acute sickle cell crisis pain episodes evolve over four distinctive phases: prodromal, initial, established, and resolving. The first phase, the prodromal phase, can last from one to four days and is characterized by pain, weakness, fatigue, and loss of appetite, with a possibility of respiratory symptoms or fever. The initial phase (actually the second phase of the four) can overlap with the prodromal phase and can last one to four days also, this phase is characterized by worsening pain, irreversibly sickled cells, dense red blood cells, increased hemoglobin distribution width (HDW), and increased red cell distribution width (RDW). The third phase, labelled as the established phase, can last from three to six days and is characterized by, possible leukocytosis, possible increased temperatures, increased reticulocyte counts, elevated lactate dehydrogenase, and possible increases in C - reactive protein and serum amyloid, with possible decrease in hemoglobin. The fourth phase, called the resolving phase, can last seven to ten days and is characterized by stabilized RDW and HDW, decrease in dense red blood cells, decrease in irreversibly sickled cells, possible increase in plasma viscosity, increase in platelet counts, with possible increase in fibrinogen, and erythrocyte sedimentation rates (Ballas, 1995 & Ballas, 2007).

## Complications of Sickle Cell Disease

The many complications of sickle cell disease (SCD) may be directly correlated to the effects of vaso-occlusive crisis pain episodes. Providers are most familiar with the hallmark symptom, which is vaso-occlusive crisis pain. The onset of multiple ischemic periods and the resulting occlusions force individuals with sickle cell disease to live with a plethora of conditions related to these phenomena, which include:

- chronic pain
- fatigue
- Priapism
- renal failure
- pulmonary hypertension
- hypertension
- neuropathy
- delayed growth and puberty
- strokes
- cholelithiasis
- retinopathy
- blindness
- splenic sequestration
- cardiomyopathy
- bacterial infections
- acute chest syndrome

- avascular necrosis
- leg ulcers
- aplastic episodes
- depression
- hepatic sequestration

Often these individuals experience acute pain along with chronic pain-pain they experience daily and these occurrences can often overlap. This makes it more difficult for patients, and providers to distinguish the difference between the chronic and the acute pain experienced during vaso-occlusive pain episodes (Ballas, 2010; Dunlop, 2006; Field et al., 2009; Platt et al., 2002; Wang, 2007). In recent years, Hydroxyurea (HU) was approved for use in adults with SCD to increase the levels of their fetal hemoglobin. The increase in fetal hemoglobin has been associated with a decrease in the frequency of vaso-occlusive episodes, an improved mortality from acute chest syndrome, and a decreased need for chronic blood transfusions (Ballas et al., 2006; Steinberg et al., 2003).

**Mortality/Morbidity of Sickle Cell Disease**

There are many factors that affect the mortality and morbidity of the adult living with sickle cell disease. These include: type of SCD, age, baseline hemoglobin (Hgb) and white blood count (WBC), left ventricular function, left ventricular size, corrected QT (QTc), tricuspid regurgitant jet velocity (TRv), and pulmonary hypertension (pHTN), which is defined as TRv of at least 2.5m/sec (Fitzhugh et al., 2010). These factors often

influence the research and the discussions that compare patients with sickle cell disease and their incidence of death.

Fitzhugh et al. (2010) studied a population of 240 adult sufferers of SCD in which 43 of the subjects died during the study period. The median age for survival was 39 years for females (95% CI: 34-56), 40 years for males (95% CI: 34-48), and 40 years overall (95% CI: 35-48). The causes of death were reported as follows: cardiac causes for death accounted for 25.6% (11/43 patients); pulmonary, 14% (6/43 patients); other SCD-related, 32.6% (14/43patients); unknown, 14% (6/43patients); and others accounted for 14% (6/43 patients). More specifically, the most common causes of death amongst the patients studied were found to be cardiac arrest, pulmonary emboli, multi-organ failure, and stroke; additional research is required to determine the necessary treatments to prevent fatal cardiopulmonary complications (Fitzhugh et al., 2010). Other studies concurred that individuals living with SCD, as a group, experience a significantly shorter lifespan and have increasingly more disease-related complications that directly affect their mortality and morbidity, such as arthritis, diabetes, heart disease, chronic lung problems, and kidney disease (Ballas et al., 2006;  Fitzhugh et al., 2010; Steinberg et al., 2003).

Despite the many medical advances of the last 30 years, there remains a higher-than-average premature death rate for individuals living with sickle cell disease than those without sickle cell disease (Fitzhugh et al., 2010). Another study conducted by Ballas and Marcolina (2006), reported an average life expectancy of 45 years of age for individuals with SCD (Ballas et al., 2006). One possible explanation for this occurrence may be the inferred correlation between prolonged vaso-occlusive pain episodes and

poorly managed pain, which can lead to end-organ damage (Ballas et al., 2006; Fitzhugh et al., 2010; Steinberg et al., 2003). In recent years the cause of death and mortality in individuals living with sickle cell disease has shifted from infectious processes to cardiac or pulmonary complications (Ballas et al., 2006; Steinberg et al., 2003; Fitzhugh et al., 2010). Although adults with SCD are prone to premature mortality and increased morbidity, for children ages 6 months to 5 years with SCD mortality and morbidity are directly correlated with decreased incidences of fatal infectious processes prior to the implementation of antibiotic therapy (Ballas et al., 2006; Frei-Jones et al., 2008; Steinberg et al., 2003). Further research of this nature could help tease out the determinants of decreasing mortality and morbidity rates in adults with SCD.

Another aspect of morbidity/mortality to consider for discussion and additional research is the correlation between poorly managed vaso-occlusive crisis pain and organ damage. Organ damage occurs in individuals living with sickle cell disease as a direct result of the sickling process and damage from repeated crises (Ballas et al., 2006; Eckman, 2010; Fitzhugh et al., 2010). Researchers need to examine barriers to the usage of Hydroxyurea (HU) among SCD patients in all age groups and the possible effects of limiting the number of vaso-occlusive pain crisis events on organ damage, mortality, and morbidity. As the research that was reviewed here suggests, patient engagement and participation is needed. Likewise, it is imperative for providers to encourage the use of HU medication to determine if less vaso-occlusive crisis leads to less organ damage and to determine future treatment options for individuals living with SCD. Such work has the potential to positively impact SCD patients by decreasing

mortality and morbidity across their lifespans (Ballas et al., 2006; Eckman, 2010; Fitzhugh et al., 2010; Steinberg et al., 2010).

**Utilization of Services**

People living with sickle cell disease utilize the emergency department, inpatient facilities, and medical offices to manage and treat acute symptoms of vaso-occlusive pain crisis episodes that can no longer be managed at home. Vaso-occlusive crisis pain episodes accounted for 94.6% of the hospital admissions for patients with sickle cell disease, which usually were from the emergency department (Epstein et al., 2006). Men represent a higher percentage of admissions than women for acute painful episodes (56.6% versus 38.1% of total admissions); for men, the admissions were directly related to acute painful crisis events, while women's admissions tended to be non-crisis related (Ballas & Lusardi, 2005). It is important to note that SCD affects men, women, and children differently, and the responses for these individuals will be different depending on age, severity of disease, genotype, coping skills, and a myriad of other factors such as infection, acute chest syndrome, cardiomyopathy, and avascular necrosis.

Ballas and Lusardi (2005) conducted a study over a five-year period, in which they reviewed the inpatient information and looked at several aspects of SCD admissions, such as the number of patients admitted for vaso-occlusive crisis pain episodes (a total of 136 patients admitted for 1,540 instances), and average length of stay (ALOS), which was 7.6 days with sickle SS (Ballas & Lusardi, 2005). Admissions other than vaso-occlusive episodes were for transfusion, surgery, complications of pregnancy, delivery, trauma, and hemodialysis. Additionally, 37 of the admissions with

acute vaso-occlusive episodes also had a diagnosis of acute chest syndrome (Ballas & Lusardi 2005). Acute chest syndrome was diagnosed in 64 of the patients after admission, with a total of 101 admissions (6.6% of all admissions) with acute chest syndrome as a diagnosis. Additional diagnoses identified during hospitalization of patients with acute vaso-occlusive episodes included infections, acute chest syndrome, cardiomyopathy, and priapism (Ballas & Lusardi, 2005).

Epstein et al. (2006) reviewed 142 unique individuals' medical records for a total of 4,874 emergency department (ED) visits, of which 1,607 (33%) resulted in a hospitalization, 3,267 (67%) were independent ED usage not requiring hospitalization. These 142 unique patients were engaged in continuous service for 3-5 years, meaning they received their hematological and primary care within this system. A total of 1,681 inpatient admissions, which comprised 95.6% of the hospitalizations, originated from the ED (1,607/1,681). For the overall patient population studied, the means were 4.1 office visits per year, 7.4 total ED visits per year, 4.9 independent ED visits per year, 2.7 inpatient admissions per year and 23.2 total bed days per year. The median ED usage was only 2.5 totals, and 1.0 independent visit per year. The median admission rate was only 1.6 admissions per year, which accounted for a median 12.8 total bed days per year. The average length of stay was 6.8 days, with a median of 5.9 days (Epstein et al., 2006).

Interestingly, the main difference between the patient populations was the genotype of the sickle cell disease – homozygous sickle-S disease in the Ballas and Lusardi (2005) study, and hemoglobin sickle-C disease in the Epstein et al. (2006) study; however, the findings were very similar in nature. Again, it is important to note

there were no references made to the national guideline for pain management (NHLBI, 2002) in either of these studies. These studies reviewed the practice patterns of hospital inpatient and emergency department use and, described patterns of healthcare utilization and frequency of vaso-occlusive episode pain admissions, within large urban hospital settings (Ballas & Lusardi, 2005; Epstein et al., 2006).

Ballas and Lusardi (2005) identified the primary cause of hospital admissions were for acute vaso-occlusive pain episodes. This study consisted of 136 individual patients with an observation admission rate of 1,540 admissions during the 5-year study period (Ballas & Lusardi, 2005). Practice patterns for utilization that were observed included: 50% of the patients were readmitted within thirty days of discharge for vaso-occlusive pain episode; 16% of all patient admissions were within 1 week of discharge which included a higher mortality rate associated with readmission and required careful monitoring (Ballas & Lusardi, 2005). Causes for readmission were most frequently determined to be premature discharge, withdrawal symptoms, and new acute pain episodes (Ballas & Lusardi, 2005). When examining this information, Ballas discovered several factors for readmission which included high pain scores in 52 of the patients readmitted (higher than days 7 and 8 of their previous admissions); suboptimal plan of pain management upon discharge (patients' opioid dose at home much lower than hospital pain management causing either withdrawal or new acute pain episodes). During this 5-year study, 26 (36%) of the total number of included patients died. Of the readmitted patients, 20% died within 1 week of being hospitalized, while 14% of all sickle cell patients died within the 5-year study period (Ballas & Lusardi, 2005). It was noted during this 5-year period for adult patients with homozygous sickle-S disease and

hemoglobin sickle-C disease. The emergency department was a common place for utilization for all patients with sickle cell disease. Of these, there was a mean of 7.4 visits per patient year, of which 1/3 of the patient visits resulted in hospital admission with the primary diagnosis of a vaso-occlusive crisis pain episode (Ballas & Lusardi, 2005; Epstein et al., 2006).

Pain scores were also evaluated as part of the equation for high re-admission rates within this patient population, with a reasonable explanation for this occurrence (Ballas & Lusardi, 2005). According to Ballas and Lusardi (2005), upon the first day of admission one would predict the pain score of the individual to be at its highest, and then decreasing during the ensuing inpatient hospital days, with a marked decrease in the intensity of pain from the vaso-occlusive episode from day 1 (admission) to day 5 of hospitalization. Regression analysis shows significant decrease in the pain score between day 1 and day 8 ($r^2$ = 69%, $P$ = 0.011); the difference was even more significant between days 1 and 5 ($r^2$ = 94%, $P$ = 0.007). Regression analysis between days 5 and 8 showed no significant difference ($P$ = 0.106) (Ballas & Lusardi, 2005).

Pain intensity scores upon admission averaged m= 8.7 ± 1.24 for n=348 measurements of pain, with a range of pain scores being 6-10, and a median pain score of 9. Pain intensity scores at the time of discharge averaged m=6.6 ± 1.81 for n=348 measurements of pain, with a range of pain scores being 2-10, and median pain score of 7 (Ballas & Lusardi, 2005). With each hospital day, pain intensity scores trended downward until day 4 (day 1: n= (337) m= 8.7 ±1.17 P= <0.001 1 vs. 2-8…, day 4: n= (264) m= 7.5 ±1.60 P= <0.025 4 vs. 5-8) (Ballas & Lusardi, 2005). Pain intensity scores from day 5 until the day of discharge indicated a plateau in pain and were not

considered statistically significant [Day 5: n= (240) m= 7.3 ± 1.69 NS 5 vs. 6-8] (Ballas & Lusardi, 2005).

Several possible reasons for the moderate pain that many individuals may have been discharged experiencing included: 1. Difference in being admitted to hematology units and being managed by hematologist with interests in sickle cell disease. 2. Aggressive pain management. 3. Decision by the patient to leave due to family, job, or childcare issues. 4. Provider bias. 5. Insurance carrier rules and pressure for discharge (Ballas & Lusardi, 2005). These are significant details that need to be addressed during sickle cell disease care management in the adult population as these issues are less prevalent in pediatrics.

The lack of evidence continues to make the case for improvements in care that will lead to continuity and better quality when treating and managing patients during a vaso-occlusive crisis pain episode. Lastly, premature discharge from the hospital or suboptimal practice patterns of pain management upon discharge may result in readmissions, usually occurring within a week of discharge (Ballas & Lusardi, 2005). These studies agreed and implied the need to establish standards of care for hospitalized SCD patients with vaso-occlusive crises, with continued research needed.

It has been suggested that personal resources may play a critical role for improving the health status and the quality of life for those individuals living with the chronic illness of sickle cell disease (Jenerette & Murdaugh, 2008). The discussion of health outcomes of adults with sickle cell disease, based on their individual ability to cope, adjust, advocate and participate in their care, is a feature that is certainly needed

in the navigation of this debilitating chronic illness. The lack of evidence in this area necessitates further testing and research to fill the gap in knowledge (Bediako et al., 2007; Edwards, Telfair, Cecil, & Lenoci, 2001; Jenerette & Murdaugh, 2008).

Along with the encouragement of active participation in care and treatment, the adult care providers must also consider what barriers exist in creating relationships that allow for mutual trust and respect of the provider and patient. Self-efficacy and self-management needs to be encouraged and nurtured (Bediako et al., 2007; Edwards et al., 2001; Jenerette, & Murdaugh, 2008). Self-efficacy can be a primary variable in predicting disease symptomatology and health services utilization for adult patients with sickle cell disease (Edwards et al., 2001). Edwards et al. (2001) reported that lower self-efficacy levels in adults coincide with more physical and psychological symptoms, more severe SCD pain, and more frequent physician visits. Previous studies on fibromyalgia and arthritis denote changes in self-efficacy that were more superior forecasters of outcomes than preliminary levels of efficacy beliefs (Edwards et al., 2001). Individuals with SCD who display higher levels of self-efficacy may also demonstrate higher levels of physical and psychological health and lower risk for poor SCD adjustment (Edwards et al., 2001).

Perceived stress and psychological symptoms were significantly associated with pain severity with *r* values of 0.35 and 0.34, respectively (Bediako et al., 2007). In a sample of African Americans, Bediako et al.'s (2007) study to some extent provided an exploratory model of the confluence of racial centrality, pain, psychological symptoms, and the correlations for pain episode frequency, and health care usage. Racial centrality as defined by Sellers (1998), "refers to the extent to which a person normatively defines

himself or herself with regard to race; centrality is relatively stable across situations" (Sellers et al., 1998). According to Bediako et al. (2007), racial centrality for the purpose of this study was defined as normative self-relevance of race. Study results determined that both stress and mood play a role in the course of SCD vaso-occlusive pain crisis episodes, and that stress may precipitate vaso-occlusive pain (Porter, Gil, Carson, Anthony, & Ready, 2000). Stress and mood was shown to be significantly associated with increases in same-day pain ratings. A significant number of painful episodes were preceded by increases in more severe stressors at least two days prior to onset, suggesting that stress may be a precipitating factor of SCD vaso-occlusive pain crisis episodes (Porter et al., 2000). Mood was assessed based on positive affect (PA) that entailed pleasant emotions like joy and happiness, while negative affect (NA) was associated with emotions like sadness and fear (Porter et al., 2000). Mood was included in this study since there is mounting evidence which supports chronic illnesses impacts, pain, functional capacity and disease symptoms (Porter et al., 2000). It is also suggested that more research should be conducted in this area (Porter et al., 2000).

**Average Length of Stay**

Certain chronic illnesses such as sickle cell disease have an "average" number of hospital days associated for care and treatment. The national average for length of stay (ALOS) for an adult inpatient with vaso-occlusive crisis is 6.5 days. However, when the Regional Medical Center at Memphis (Tennessee) implemented an inpatient care delivery model for sickle cell disease patients, ALOS decreased from 5.8 days in 2002 to 4.6 days in 2007 (Adams-Graves et al., 2008). The ALOS has been shown to be decreased by the introduction of the "Day Hospital Model" and treatment protocols

specific for the management of sickle cell disease care; these models have also created effective treatment measures and substantial cost savings (Adams-Graves, 2008; Jordan, 2008). Addressing clinical practice patterns deficits by implementing quality improvements identified with the guidance of the Dartmouth Microsystem can positively influence the ALOS. A possible reduction in the number of days away from an individual's "normal life" is significant benefit to the person and family and can appreciably increase patient satisfaction.

**Financial Burden of Sickle Cell Disease**

An intriguing and important aspect of healthcare that should not be overlooked is the financial burden that chronic illness bears across the lifespan. When estimating the economic burden of illness from a health care system perspective, the Medicaid reimbursement rates are generally used as the proxy for the actual cost of care (Kauf, Coates, Huazhi, Mody-Patel, & Hartzema, 2009). It is difficult to estimate the overall cost of care for the adult SCD patient, in the case of employer-sponsored and non-Medicaid patient populations.

Kauf et al. (2009) in one study sample of 4,294 patients, aggregate health care costs usually rose with the age of the patient, from $892 to $2,562 per patient per month in the 0-9 and 50-64 year age groups, respectively. The average cost per patient-month was $1,389. Largely, 51.8% of care was directly related to SCD care issues; the preponderance of which (80.5%) was directly associated with inpatient hospitalizations (Kauf et al., 2009). Total lifetime healthcare costs can be estimated to reach as much as $953,640 for a SCD patient at age 45. The present value of lifetime costs is $460,151.

Median lifetime costs were estimated at $392,940 (Kauf et al., 2009). An important note is that the burden of care in different regions may vary, but Medicaid reimbursement remains consistent across the country.

According to Kauf et al. (2009), the "costs of care estimates are important inputs to health care planning, research prioritization, and the economic evaluation of new SCD treatment strategies." Several studies reiterated some very important topics regarding SCD. Some of these include sickle cell disease morbidity, which remains persistently high; the need for improved treatments; interventions designed to prevent complications; and avoidance of hospitalization; and reductions in the economic burdens of the disease (Ballas & Lusardi, 2005; Bediako et al., 2007; Epstein, Yuen, Riggio, Ballas, & Moleski, 2006; Frei-Jones et al., 2008; Kauf et al., 2009; Telfair et al., 2003).

**Clinical Practice Guidelines and Protocols**

Several studies have addressed clinical practice pattern elements such as treatment protocols, and/or standardized care, reduction of hospital-associated costs, improvement of pain management as a direct effect of the standardization of care, reduction in length of stay, patient satisfaction, and the role of the family and health care providers for individuals that live with SCD (Adams-Graves, et al., 2008; Frei-Jones et al., 2009; Givens et al., 2007). One of the approaches to creating more effective treatment options and improved outcomes has been the development and implementation of the sickle cell, hospital day unit for the provision of care for adult SCD patients (Adams-Graves, et al., 2008).

One example of the benefits of treatment protocols and guidelines with the implementation of the sickle cell hospital model has been at Diggs-Kraus Sickle Cell Center in Memphis, Tennessee (MED). This facility provides services to 450 adults with SCD and receives an average of 2,000 visits per year. The MED serves an adult population that is comprised of 95% over the age of 21 years, with a female population of 53% (Adams-Graves et al., 2008). The ethnicity of this patient population is primarily African American, except for one patient of Hispanic descent. The chief medical requirements for admittance at the MED for individuals with SCD do not specify crisis pain as admission criteria.

The results of creating and implementing the inpatient care model with the SCD unit triggered a reduction in the use of the emergency department, improved SCD care, and improved patient/family satisfaction (Adams-Graves et al., 2008). The implementation of standardized admission orders and guidelines for inpatient management and treatment, and the implementation of standardized treatment protocols for the emergency department care of individuals suffering from vaso-occlusive crisis pain episodes all yielded the same kind of results for individuals at acute care facilities. Implementing the inpatient care model with the SCD unit had a positive outcome for the care of the sickle cell patients, which was indicated with a marked decrease in ED visits by sickle cell patients after implementation of pain management guidelines and increasingly proactive efforts by the Hematology Clinic to bring their patients back to the clinic and into sickle cell day hospitals (Adams-Graves et al., 2008; Givens et al., 2007). Total hospital visits did not change significantly in any of the 4 years, ($p$>0.10) under comparison. Total ED visits decreased significantly over the 4-

year period ($p$<0.001), whereas clinic visits steadily increased ($p$<0.001). Return visits to the ED within 30 days also declined significantly ($p$<0.001) (Givens et al., 2007). Also, the number of admissions per year and the total admissions per hospital visit declined markedly over time in both studies. However, the total hospital admissions did not change, but the proportion of ED visits that resulted in admission in year 1 (29%) was significantly lower than the proportion admitted in year 2 (43%), $p$=0.04. Two major causes for this change were that (a) the use of pain protocol using morphine or hydromorphone coupled with (b) increased access to outpatient clinics decreased ED visits, hospitalization, and also the increased utilization of a more stable primary care clinic setting by patients with SCD (Adams-Graves et al., 2008; Givens et al., 2007).

These results demonstrate the need to continue research for improving clinical practice and management of vaso-occlusive pain episodes of SCD. This further stresses the importance and the need for high-quality sickle cell care and management in inpatient and outpatient settings, both of which can enhance the quality of care, decrease hospital-associated cost, and improve acute pain management of patients (Adams-Graves et al., 2008; Frei-Jones et al., 2009; Givens et al., 2007). It is critical for researchers to further explore clinical practice patterns and the impact for SCD on the quality of pain management for all patients with chronic or recurrent pain, patient perception of ED pain management and the relationship of non-emergency sources of care (Givens et al., 2007).

Rees (2003) recommended a written protocol for patients admitted for vaso-occlusive episode, with a multidisciplinary approach to management. According to Rees, (2003) the following is recommended:

- Sickle cell trait is not likely to cause pain and should not be considered the source of pain.
- Identification cards with individualized treatment requirements and baseline information should be issued to sickle cell disease patients.
- Nitrous oxides can be administered while being treated in the ambulance not to be used frequently or for more than 1 hour.
- Pain medications should be administered within 30 minutes of “entering the hospital”, with effective analgesia within 60 minutes.
- Assessments of pain, respiratory rate and sedation should be assessed “every 20minutes until pain is controlled”.
- This recommendation also strongly states that Demerol/Meperidine should not be administered for pain control in SCD patients.

The National Institute for Health and Clinical Excellence (NICE, 2012) created guidelines for the management of acute painful sickle cell episodes while hospitalized for the individual with vaso-occlusive pain episode across the lifespan which included, children, adolescents, and pregnant women. This guideline was created to help decrease the variability in care for the United Kingdom, and education for optimal management. The recommendations included:

- Patient centered care.
- Individualized assessments-treat the pain event as a medical emergency, ascertain which treatments worked for previous episodes, listen to the patient.

- Assess pain and offer analgesia within 30 minutes of presentation at hospital.
- Assess and monitor blood pressure, oxygen saturation, pulse rate, and temperature.
- Properly administer medications which include opioids, and adjuvants
- Frequent and ongoing assessments every 30minutes initially and at least every 4 hours once pain relief has been achieved.
- Consider acute complications: abnormal respiratory signs and symptoms, chest pain, fever, infection, and hypoxia.
- Do not administer Demerol/Meperidine.
- Healthcare professionals should receive ongoing training, topics should include: pain relief, identifying complications, and attitude and presumptions regarding patients presenting in acute sickle cell pain.

The NICE guidelines (2012) did not make medication recommendations for the treatment of vaso-occlusive pain for each area has locally agreed protocols that should be followed which do included opioids, and adjuvants.

The NHLBI guideline recommendations are an important aspect of care for the individual experiencing a vaso-occlusive crisis pain episode. The current NHLBI (2002) emergency treatment of acute pain episode guidelines state:

> *Patients should undergo a thorough history and physical examination to determine whether an illness might have precipitated the pain, so that the cause and symptom can be treated simultaneously. Patients should be*

*seen immediately by a physician if they experience severe abdominal pain, recurrent vomiting, respiratory symptoms, neurologic signs of paresis or paralysis, acute joint swelling, priapism, or abrupt fall in hemoglobin. Superimposition of acute pain on chronic pain may confound assessment and treatment.*

All patients should undergo rapid assessment with frequent reassessments for acute pain episode. Pain management should be aggressive to relieve pain and achieve maximum function expediently. Severe pain in SCD should be considered a medical emergency which therefore needs prompt and timely treatment. The 2002 NHLBI guidelines make the following recommendations for treatment:

1. Begin hydration: the initial fluid should be 5% dextrose + half-normal saline with 20 mEq KCL/L adjusted for serum chemistries.
2. Assess the cause of pain and any complications. Determine medications or treatments taken at home, including usual drugs and dosages, and any potential side effects during acute pain. Then use the opioid dosage which provided adequate analgesia at a previous time engaged in care (for the patients known to a practice with a previous treatment history).
3. Avoid intramuscular injections. However, if unable to obtain intravenous access, the subcutaneous route for administration of opioids is effective and acceptable.
4. Frequent assessments of pain intensity, relief, mood, and sedation level are required every 15 to 30 minutes after each dose of medication.
5. Titration to relief is an important aspect of care, regarding the nature of recurrent pain episodes and for consistent management of acute pain episodes. Titration

can be achieved with aggressive dosing and with frequent or close monitoring; bolus dosing should be set at timed intervals after a loading dose, or “by the clock” (BTC) dosing, such as morphine 4 mg every 2 hours.

6. Disposition at the conclusion of treatment must also be considered, whether an individual is being discharged from the ED or from the inpatient setting. Individuals need prescriptions for equivalent doses of pain medication to maintain pain relief. However, after aggressive treatment is given and pain relief is not achieved, inpatient admission should be considered (NHLBI, 2002).

**Provider Knowledge**

It has been acknowledged that the education of the health care providers is pivotal to the success of any practice change, especially in a cohort of patients that are deemed “chronic” or high utilizers of care (Aisiku et al., 2007; Fitzhugh et al., 2010). There is a serious gap in the knowledge base of the providers in the area of treatment and management of the adult in vaso-occlusive pain crisis episodes; this can certainly be a topic for future studies, since this gap in knowledge may further prevent providers from more rapidly responding to patients’ requests for changes to treatments and medication regimens (Adams-Graves et al., 2008; Ballas & Lusardi, 2005; Aisiku et al., 2009; Epstein et al., 2006). Studies have shown that individuals who are in a vaso-occlusive pain crisis episode and treated in a sickle-cell specific care center have higher patient satisfaction scores, more aggressive treatment, and improved overall pain management when compared to individuals who receive care in non-specific treatment centers (Adams-Graves et al., 2008; Aisiku et al., 2007; Ballas, 2010; Benjamin et al., 2000; Field et al., 2009; Givens et al., 2007; Haywood et al., 2009; Smith et al., 2005).

Solomon (2008) found that treatment and management of vaso-occlusive pain crisis episodes in SCD patients were not given much attention in medical training materials, with specific management recommendations in only “4 of 19 medical textbooks." This study further reiterated information from similar research conducted by Smith et al. (2005) and Benjamin et al. (2000); namely, providers of care for SCD vary greatly in their knowledge of SCD in general and of opioid usage. They also frequently possess possible prejudicial barriers and predetermined judgments regarding “drug-seeking” behaviors of individuals with sickle cell disease in vaso-occlusive pain crisis episodes, deeming these patients to be “frequent flyers” or “needing a fix” (Adams-Graves et al., 2008; Ballas, 2010; Benjamin et al., 2000; Smith et al., 2005; Solomon, 2008; Jordan, 2008). The pain of SCD is real and requires non-prejudicial and engaged care providers to manage the symptomology and pain manifestations of this disease. Studies have shown that when SCD care providers are trained to manage the health issue, patient satisfaction and outcomes are improved – “practice makes for improved care” (Jordan, 2008; Adams-Graves et al., 2008; Ballas, 2010; Benjamin et al., 2000; Aisiku et al., 2007).

**Clinical Practice Patterns for Treatment**

Significant differences exist in the care of children and adults in vaso-occlusive pain crisis episodes. One difference for children is that the barrier of mistrust does not yet exist (Field et al., 2009; Jenerette & Murdaugh, 2008). Drug-seeking behaviors, although they may exist in pediatric populations, are not treated in the same manner as adults; the children are assessed for adequate pain management and treated accordingly. This approach is not always extended to the adult population, where

mistrust and judgmental care can be evident (Aisiku et al., 2007; Ballas, 2010; Ballas & Lusardi, 2005; Givens et al., 2007).

The implementation of standardized sickle cell treatment guidelines and protocols suggests these clinical practice recommendations may be cost saving in nature, while reducing hospital readmission in the same population (sickle cell disease), with patient-focused quality measures such as: reduction in pain score upon discharge, and reduction in complications associated with admission for pain (Ballas & Lusardi, 2005; Epstein et al., 2006; Frei-Jones et al., 2009). During the evaluation of the utilization of guidelines that were implemented overall, pain management was improved, and admissions were decreased or made significantly shorter in a few limited practice locations (Frei-Jones et al., 2008; Frei-Jones et al., 2009). These practice guidelines allowed for more aggressive treatment in the emergency department, which had a tremendous impact on the admission and readmission rate of individuals seeking treatment for vaso-occlusive pain crisis episodes. During these studies, the patients in the ED received treatment in a timelier fashion, and had more adequate pain management, for example, adequate opioid dosing and use, decreased times for dose administration, longer time with the clinician for treatment and assessment (Ballas & Lusardi, 2005; Epstein et al., 2006; Givens et al., 2007; Frei-Jones et al., 2008; Frei-Jones et al., 2009).

In clinical practice patterns for children in vaso-occlusive crisis pain episodes with standardized guidelines, similar patterns of utilization have been assessed by using pediatric measures rather than adult measures. The participants' pain was assessed by the ED physician and/or the hematologist using the standard scale for children, which is

the 0 to 5 Wong-Baker FACES scale; they rarely used the scale of 0 to 10 with children. Other differences included the number of morphine doses received, and child's/parent's comfort level (Frei-Jones et al., 2008). Patients, for whom the protocols were used, received more doses of morphine, with significantly improved pain relief than those individual patients with whom the protocol was not used (Frei-Jones et al., 2008). As several studies have noted, suboptimal pain relief is addressed as an issue that needs further investigation for the improvement of pain management for individuals who suffer from vaso-occlusive pain episodes (Ballas & Lusardi, 2005; Epstein et al., 2006; Frei-Jones et al., 2008).

Studies dealing with adult inpatients in settings with clinical practice guidelines or protocols in place versus patients that had their treatment in a general facility or a facility that did not have clinical practice guidelines to follow had similar findings to the previous pediatric study described (Adams-Graves et al., 2008; Aisiku et al., 2007; Givens et al., 2007; Frei-Jones et al., 2009). Namely, patients and providers were more satisfied with care, opioid dosing was more appropriate which improved analgesia, medications were given in a timely fashion, and attitudes of the providers were better concerning potentially "drug-seeking" behaviors that were often otherwise dismissed in non-specific treatment centers (Adams-Graves et al., 2008; Aisiku et al., 2007; Frei-Jones et al., 2009; Givens et al., 2007; Jordan, 2008; Smith et al., 2005). A collaborative team approach between generalists/hospitalists, continuity of care (same provider or provider team) during and post hospitalization, and planning for care or establishing a plan of care ought to be considered to improve the overall management

of the sickle cell patient in vaso-occlusive crisis pain episodes (Ballas & Lusardi, 2005; Epstein et al., 2006).

**Summary of Chapter**

A methodical review of the literature was completed to ascertain information regarding utilization and impact of clinical practice guidelines in relation to the management of hospitalized adults with sickle cell disease in vaso-occlusive crisis pain. The research that is available is specific to either children or to the emergency department management of adults. There is very little literature specific to the adult inpatient population for the management and treatment of vaso-occlusive crisis pain episodes. The minimal literature made references to improving the timeliness of initiation of care, administering appropriate and adequate analgesia, which could improve SCD vaso-occlusive crisis pain management, patient satisfaction, and reduction in the number of inpatient hospital days. One of the most important commonalities of the research was that when treatment guidelines, protocols, or treatment plans were in place, the overall care and management of the patient suffering from vaso-occlusive crisis episode pain showed general improvement compared to care received in non-specific treatment facilities or from providers whose mistrust issues could negatively impact clinical practice (Adams-Graves, P., Ostric, E. J., Martin, M., Richardson, P., & Lewis Jr, J. B.,2008; Ballas & Marcolina, 2006; Givens et al., 2007).

However, the protocols that have been identified in the literature did not focus on the first twenty-four hours of admission, a critical timeframe for the resolution of severe pain from a vaso-occlusive crisis pain episode. In addition, a specialized

treatment protocol identified in an SCD specific facility is not available for replication in other treatment facilities, and has not been published in the literature/research to date. This quality improvement project addressed these gaps by comparing the current clinical practice patterns for vaso-occlusive crisis pain management and treatment to the NHLBI guidelines to identify optimal clinical practice patterns for the first 24 hours of care for the hospitalized adult. Once the clinical practice deficits were identified, the results were utilized to develop the clinical dashboard. The clinical dashboard will be used to monitor the measures or outcomes that have been recommended for performance and quality improvement, and will be evaluated prospectively, to improve the quality of clinical practices and create change that will optimize the highest quality evidenced based practice for the adult experiencing vaso-occlusive crisis pain.

The critical review of existing literature was greatly needed to help identify the current clinical practices. The lack of research in the adult sickle cell population makes the determination of deficits for improving the quality of care paramount for creating evidenced based practices to guide high quality sickle cell care. The literature review provided the foundation for this project.

# Chapter 3

# Methods

## Design

This was a quality improvement project that utilized a retrospective medical record review to compare current clinical practice patterns during the first 24 hours of inpatient and the first 24 hours of observation status care for adults admitted with a sickle cell pain episode to current guidelines of the NHLBI for emergency department care utilizing the Dartmouth Microsystem quality improvement initiatives. This quality improvement project focused on data from the treatment provided within the initial 24 hours of patient hospitalization in regards to patient assessments, utilization of intravenous fluids, oxygen administration, choice of pain medications including opioids, NSAIDS and other adjuvants medications. This QI project identified clinical practice patterns for adults hospitalized or on observation status for sickle cell pain and compared the practice patterns to the NHLBI guidelines.

## Setting and Sample

This quality improvement project was conducted at a suburban university health center. The facility is a 225-bed facility in central Connecticut that provides general acute care services and is a prominent teaching hospital in New England. Prior to this project, a historic review of the utilization data was completed looking at the time period from 4/1/2012-3/30/2014. There were 219 vaso-occlusive crisis admissions from 4/1/2012 through 3/30/2013 for 1988 inpatient days with an ALOS of 9.07 days, and 209 admissions from 4/1/2013 through 3/30/2014 with 974 inpatient days with ALOS of 4.66

days (Utilization Data, 2014). In October of 2012, the facility's Comprehensive Adult Sickle Cell Program acquired a full team of providers to treat and manage the sickle cell patients. The team included a full-time nurse practitioner, a full time social worker, along with the full time registered nurse that had been with the program starting the previous year. This enabled comprehensive care and full engagement of the team in- and outpatient care settings with the adult sickle cell patients. The Sickle Cell Comprehensive Care Center facility offers many services which include diagnosis of sickle cell disease, ongoing ambulatory care and treatment, same day episode pain management, and many other services all related to the management of sickle cell disease.

The data source was a convenience sample of medical records for adults admitted to the inpatient units for a vaso-occlusive crisis pain episode in the facility during a 12-month period (January 2014-December 2014). All were ages 18 years and older with confirmed sickle cell disease with one of the following variants: SS, SC, β+, or βº. For the purposes of this project, the medical records were used to verify documentation of disease with hemoglobin electrophoresis or other similar test results for sickle S disease, sickle C disease, and sickle Thalassemia. The medical record of the admitted adult had a primary or secondary diagnosis of acute vaso-occlusive pain episode which required inpatient treatment or observation status for the management of the pain episode.

All admissions were counted regardless of the number of admissions during the one-year time period for each patient. These inpatient admissions and observation status admissions occurred through the emergency department or direct admission. For

the purpose of this quality improvement project, the first 24 hours of inpatient admission was defined as the time from the patient's documented arrival to the inpatient unit and the proceeding 24 hours after arrival. Likewise, for the purpose of this quality improvement project, the first 24 hours of observation status admission was defined as the time of the patient's documented arrival to the inpatient unit and the proceeding 24 hours after arrival, unless that admission was changed to inpatient within the 24-hour timeframe. The following medical records were excluded from this project: individuals who were younger than 18 years of age and/or patients' whose admission records did not indicate acute sickle cell pain as the primary or secondary diagnosis.

**Project Instrument**

Sickle Cell Audit Record Data Sheet (SCARDS)

The medical record abstraction form for sickle cell disease called the Sickle Cell Audit Record Data Sheet (SCARDS - Appendix A) was created by the student investigator. The SCARDS form is a compilation of information based on an Excel spreadsheet that was used to collect information from the medical record during data abstraction. The data collected for this project included: age, race, gender, marital status, disease genotype, admission date and time, discharge date and time, primary and secondary diagnosis, frequency of vital signs, including pulse oximetry and weight (if recorded), use of oxygen (including amount and the apparatus such as nasal cannula, oxygen mask, and/or nebulizer equipment) when pulse oximetry <96% (to prevent further sickling and provide an oxygen rich environment to decrease pain intensity by improving the ability of red blood cells to profuse tissues), frequency of

assessments (as recorded in the medical record), pain intensity and timing of each assessment, frequency of titrations (timing in relation to pain intensity score), administration of intravenous fluids (type, rate, potassium repletion and dosage/volume), use of opioid medications (dosage, frequency, and route of administration: IV, SQ or via PCA), use of adjuvant medications (medication, dosage, route, frequency and timing of the medication), home medications, oral intake, output, allergies, and admission status of inpatient or observation.

**Procedure**

Institutional Review Board (IRB) approval was obtained from the hospital to conduct this study. The quality improvement project utilized the Dartmouth Microsystem quality improvement initiatives:

1. Collected data to determine and compare the current clinical practice patterns of care for adults with SCD during the first 24 hours of inpatient admission with the NHLBI emergency department guidelines which give initial recommendations for inpatient management.
2. Collected data to determine and compare the current clinical practice patterns of care for adults with SCD during the first 24 hours of observation status admission with the NHLBI emergency department guidelines which give initial recommendations for inpatient management.
3. Analyzed the data collected to determine clinical practice pattern deficits based on the NHLBI emergency department guidelines.

Following IRB approval, the student co-investigator formally requested a list of patients admitted for vaso-occlusive crisis treatment during the study period. The patient list was password-protected and secured on a password-protected and/or encrypted device. Patient names were randomly ordered and assigned a unique identifier to increase protection of patient identification. After randomization for the patient list each medical record that was accessed was assigned an identifier for data collection for example 01. The protected information was used to complete the medical record review and data abstraction. The data sources for the retrospective medical record review were the medical records of identified adults with SCD admitted to the hospital for either inpatient or observation status care. Specifically, data extraction was for information regarding the patients' treatment for the first 24 hours of their hospitalization once arrived to the inpatient unit regardless of admission status. The outpatient medical record was reviewed for data not available during hospitalization including hemoglobin genotype.

The timespan for data abstraction for each inpatient and observation status admission was January 1, 2014 through December 31, 2014. The data abstraction form developed by the student investigator contained the variables of interest that were utilized to collect the data. Each inpatient or observation status admission was given a unique sequential number identifier, such as 01, which assured patient anonymity and de-identified data.

The completed de-identified data abstraction forms were stored securely on an encrypted computer and an encrypted USB storage device whereby both the student investigator and the major advisor had access to readily retrieve the stored information.

The student co-investigator completed all data abstraction. Upon completion of data collection from the medical records, the data were analyzed by imputing the collected information into the statistical program SPSS. The retrospective medical record data abstraction was based on the following variables, as recommended by the NHLBI guidelines:

- Assessment and frequent reassessment of pain in a SCD vaso-occlusive crisis pain episode (pain score, timing).
- Intravenous fluids (type/rate) and potassium repletion (if indicated), determined by intake data.
- Use of supplemental oxygen for 92-95% pulse oximetry measurements that were recorded in the medical record as part of the completed vital signs.
- Opioids and adjuvant medications (medication, dose, route, and frequency).

The following data were collected on paper using the SCARDS sheets: age, gender, genotype, primary diagnosis, secondary diagnosis, vital signs frequency including pulse oximetry measurements, intravenous access type or subcutaneous access for the administration of medications and fluids, intravenous fluids and medications being administered, medications administered for the first 24 hours of the inpatient admission and observation status admission, supplemental oxygen use, and date of admission and date of discharge. Data was inputted in the SPSS data file and reviewed by the student co-investigator for inaccurate entries, typographical errors, and

incorrect characters. Data documented on paper were stored in a locked file cabinet in the student co-investigators office at the hospital with access only by the student investigator and major advisor. This information was maintained until completion of the quality improvement project and will be destroyed in five years from completion of the project.

Data safety was maintained throughout the study by the student investigator, by implementing the following procedures:

- All data for were collected and entered by the student co-investigator.
- Data collection sheets were locked in a cabinet until the completion of the quality improvement project.
- All data were imported directly into SPSS for analysis at the completion of collection.

**Analysis**

This quality improvement project was designed to serve as baseline information for the enhancement of current clinical practices for the hospitalized adult with a sickle cell vaso-occlusive pain episode as recommended by the NHLBI clinical guidelines.

Descriptive statistics were used to analyze the data collected from the medical record chart abstraction. The demographic information from the medical records included frequencies for nominal and ordinal level measures and frequencies, means, and standard deviations for interval and higher level measures. The study variables listed for determining current clinical practices were also analyzed by the same process: primary diagnosis, secondary diagnosis, vital sign frequency, intravenous

access, intravenous fluids, opioid medications administered, adjuvant medications administered for the first twenty-four hours of the admission and observation status, the use of oxygen for pulse oximetry of <96%, genotype, and frequency of assessment and reassessments were compared to the NHLBI clinical guidelines to identify practice gaps.

A clinical dashboard was created for the quality improvement measures recommendations after the completion of the data analysis. The clinical dashboard has become the tool used to measure in a systematic and ongoing method the outcomes deemed relevant to improve the overall quality of care to close the practice gaps during the first 24 hours of the inpatient and observation status admissions. This dashboard was created and presented to administrative leadership (nursing and medical) which provided consensus for quality improvement.

**Summary**

In conclusion, this quality improvement project involved a retrospective chart review covering a time span of 12 months at an academic suburban hospital site. The abstracted information was used to compare clinical practices regarding the treatment and management of the adult sickle cell patient in a vaso-occlusive pain crisis episode while hospitalized to the national guidelines for emergency department treatment published by the NHLBI. This quality improvement project sought information to determine current clinical practice deficits and the institutional patterns to bring them in line during the initial 24 hours of inpatient admission and the initial 24 hours of the observation status admission of SCD pain events. This helped to define which clinical

practice changes were needed to improve the overall care and management of the adult hospitalized for a vaso-occlusive crisis pain episodes. This study provided the necessary data for future practice and research regarding inpatient management of the adult sickle cell patient.

# Chapter Four

## Results

This chapter provides the results of the quality improvement project that utilized a retrospective medical record review. This was a comparison of current clinical practice patterns during the first 24 hours of inpatient and the first 24 hours of observation status care for adults admitted with a sickle cell pain episode to current guidelines of the NHLBI for emergency department care utilizing the Dartmouth Microsystem quality improvement initiatives. The data presented here described the inpatient status medical records reviewed first, followed by a description of the observation status medical records data.

### Eligible Medical Records

The total number of medical records reviewed for this post-hoc analysis was 234 records from the study period covering January 1, 2014 through December 31, 2014. Of 234 records both inpatient/outpatient observation encounters 66 records were excluded from this study as they did not meet the criteria of either primary or secondary diagnosis of vaso-occlusive crisis pain. There were 117 eligible inpatient encounters for project inclusion, and 51 outpatient observation encounters eligible for project inclusion, which were reviewed. For the 117-inpatient encounter admissions, 112 were admissions to the Oncology Unit, 4 were admissions to the Medicine Unit, with 1 admission to the Multi-Specialty Unit. For the 51 observation encounter admissions, forty-seven were admitted to the Oncology Unit, and the other four encounters were admitted to the Medicine Unit.

## Demographics

The age of the individuals in the sample (N=54) ranged from 21 to 56 years of age. The mean age was 31.08 (SD ± 9.48) years of age. Of these 54-unique medical records n = 23 (42.6 %) were male and n=31 (57.4%) were female. A total of n=48 (88.9%) were Black or African American, n=5 (9.3%) were Hispanic/Latino, n=1 (1.9%) was Caucasian or White. Additionally, the marital status and genotypes are displayed for these individuals in Table 2.

Vital signs were reviewed for 168 individual encounters. 164 encounters (97.6%) had vital signs at least every four hours as recommended by the NHLBI 2002 guidelines. An important additional assessment usually associated with vital signs measurements included assessments for oxygen saturation rates or pulse oximetry levels. Pulse oximetry measurements were recorded for 117-inpatient encounters. The ranges for these measurements were 92% oxygenation to 100% oxygenation and are described in Table 3. There was one record with undocumented data. For fifty-one recorded pulse oximetry measurements for observation encounters with the range of 90% oxygenation to 100% oxygenation are also described in Table 3. Table 3 contains the descriptive characteristics of the recorded pulse oximetry levels. Continuous capnography for oxygenation was a requirement when individuals were treated with continuous or basal rate dosing of an opioid.

**Table 2.**

**Demographic Information (n=54)**

| Demographics | n | Percentage |
|---|---|---|
| Gender | | |
| Male | 23 | 42.6% |
| Female | 31 | 57.4% |
| Race | | |
| African American | 48 | 88.9% |
| White | 1 | 1.9% |
| Hispanics | 5 | 9.3% |
| Marital Status | | |
| Single | 45 | 83.3% |
| Married | 5 | 9.3% |
| Divorced | 4 | 7.4% |
| Genotype | | |
| HgSS | 38 | 70.4% |
| HgSC | 10 | 18.5% |
| HgSB+ | 6 | 11.1% |

**Table 3.**

**Pulse Oximetry Measurements (N = 168)**

| Inpatient Oximetry (n=117) | | | Observation Oximetry (n=51) | | |
|---|---|---|---|---|---|
| Measurements | n | % | Measurements | n | % |
| 90 | 0 | 0 | 90 | 1 | 2.0% |
| 92 | 2 | 1.7% | 92 | 1 | 2.0% |
| 93 | 6 | 5.2% | 93 | 1 | 2.0% |
| 94 | 8 | 6.9% | 94 | 3 | 5.9% |
| 95 | 9 | 7.8% | 95 | 2 | 3.9% |
| 96 | 9 | 7.8% | 96 | 4 | 7.8% |
| 97 | 14 | 12.1% | 97 | 6 | 11.8% |
| 98 | 19 | 16.2% | 98 | 9 | 17.6% |
| 99 | 22 | 19.0% | 99 | 15 | 29.4% |
| 100 | 27 | 23.3% | 100 | 9 | 17.6% |
| No documented data | 1 | 0.9% | | | |

**Pain**

The assessment and evaluation of pain was a crucial element for this quality improvement project. The mean pain intensity level measured over the first 24 hours of the inpatient admission was 7.48 with (SD±1.89). For the pain intensity of the inpatient encounters there was one medical record noted to be missing and one medical record

was noted to be missing for the observation encounters. There were 51 observation encounters reviewed for pain intensity scores with the same measurement scale as the inpatient encounters. The mean pain intensity level for the observation encounters was 7.92 with (SD ± 1.48).

Table 4**.**

**Pain Intensity Scores**

| Inpatient | | | Observation | | |
|---|---|---|---|---|---|
| Pain Intensity Scores | n | Percentage | Pain Intensity Scores | n | Percentage |
| 0 | 1 | 0.9 | 0 | 0 | 0.0 |
| 1 | 0 | 0.0 | 1 | 0 | 0.0 |
| 2 | 0 | 0.0 | 2 | 0 | 0.0 |
| 3 | 1 | 0.9 | 3 | 0 | 0.0 |
| 4 | 5 | 4.3 | 4 | 0 | 0.0 |
| 5 | 9 | 7.8 | 5 | 4 | 8.0 |
| 6 | 20 | 17.2 | 6 | 6 | 12.0 |
| 7 | 17 | 14.7 | 7 | 6 | 12.0 |
| 8 | 26 | 22.3 | 8 | 16 | 32.0 |
| 9 | 17 | 14.7 | 9 | 10 | 20.0 |
| 10 | 20 | 17.2 | 10 | 8 | 16.0 |
| No documented scores | 1 | | | 1 | |

Patient-reported acceptable levels of pain were also reviewed separately and were abstracted from the medical record as “yes” and “no” responses. More than half of all patients, regardless of hospitalization status, needed further intervention. Of 117 medical records reviewed for inpatient encounters only 28 (23.9%) had recorded

values; the observation encounters totaling 51 had 7 (14.0%) with recorded values with one undocumented data record.

Patient reported pain goals were recorded as part of the pain management assessment for both the inpatient and observation encounters. The mean patient reported pain goal for the inpatient encounters for 117 medical records reviewed was 3.0 with (SD± 2.19). The inpatient encounters had 61 (52.1%) records without data recorded. The observation encounters for 51 medical records reviewed had a mean patient reported pain goal of 2.5 with (SD± 2.37), with 31 records (60.8%) without data recorded. Please refer to Table 5 for the descriptive characteristics described.

**Table 5.**

**Patient Pain Goals**

| Inpatient (n=56) | | | Observation (n=20) | | |
|---|---|---|---|---|---|
| Patient Desired Pain Goal | | | Patient Desired Pain Goal | | |
| Pain Goal | n | Percentage | Pain Goal | n | Percentage |
| 0 | 15 | 26.8 | 0 | 8 | 40.0 |
| 2 | 2 | 3.6 | 2 | 2 | 10.0 |
| 3 | 15 | 26.8 | 3 | 2 | 10.0 |
| 4 | 11 | 19.6 | 4 | 5 | 25.0 |
| 5 | 3 | 5.4 | 5 | 0 | 0 |
| 6 | 8 | 14.3 | 6 | 2 | 10.0 |
| 7 | 2 | 3.6 | 7 | 1 | 5.0 |

Note. Data was not documented for n = 61 inpatient and 31 observation patient stays.

**Medical Interventions:**

The administration of oxygen was seen more often in use in clinical practice than pulse oximetry based NHLBI, 2002 recommendations for indicated use with the reference range of 92-95% for supplemental oxygen. Of the 117 inpatient medical records reviewed n=56 (47.9%) reported the use of oxygen. Of the 51-observation status, medical records reviewed n=20 (39.2%) reported the use of oxygen.

The management of vaso-occlusive pain episodes required the use of intravenous fluids for hydration and to decrease viscosity of sickling blood, which is part of the pathophysiology of a vaso-occlusive pain episode. There are many different types of intravenous fluids readily available for administration during medical care. For the euvolemic patient the goal of maintaining homeostasis dictates the intravenous fluid to be administered. The NHLBI 2002, recommends the sickle cell patient be given as "the initial fluid 5 percent dextrose and half-normal saline". The most commonly administered intravenous fluids used in clinical practice during the first 24 hours of inpatient and the first 24 hours of observation status care for adults admitted with a sickle cell pain episode to current guidelines of the NHLBI were noted here.

Per the NHLBI recommendations the IVF of choice was D5 NS 0.45% which as described here was underutilized in both inpatient and observation encounters. There was a total of 6 encounters in which no IVF was administered; the medical records did not indicate why fluids were not administered as recommended by the NHLBI, 2002. The three most commonly used intravenous fluids administered are described here in Table 6.

**Table 6.**

**Intravenous Fluids**

| IVFs (Inpatient) | n | % | IVFs (Observation) | n | % |
|---|---|---|---|---|---|
| D5 NS 0.45% | 46 | 40.0 | D5 NS 0.45% | 21 | 44.7 |
| NS 0.9% | 19 | 16.5 | NS 0.9% | 7 | 14.9 |
| NS 0.45% | 50 | 43.5 | NS 0.45% | 19 | 40.4 |
| No documented data | 2 | | No documented data | 4 | |

For the 117-inpatient encounter, medical records reviewed the mean intravenous fluid (IVF) rate was 110mL/hour with (SD ± 25.85). The range for the intravenous fluids administered was minimum IVF rate was 50mL/hour with a maximum of 175mL/hour. For the 51 observation encounter medical records reviewed the mean IVF rate was 110mL/hour with (SD ± 25.29). The range for the intravenous fluids administered was minimum IVF rate was 50mL/hour with a maximum of 175mL/hour, which was the similar findings for the inpatient encounters. For the medical records reviewed regardless of hospital status based on weight the maintenance dose is 2-3 liters per day for IVFs administered, IVFs rates were determined less than adequate in 59% of the inpatients and 47% of the observation patients and are described in Table 7.

**Table 7.**

**Intravenous Fluid Rates**

| Adequate Rate (Inpatient) | n | % | Adequate Rate (Observation) | n | % |
|---|---|---|---|---|---|
| Yes | 46 | 39.3 | Yes | 21 | 41.2 |
| Too low | 69 | 59.0 | Too low | 24 | 47.1 |
| Too much | 0 | 0 | Too much | 2 | 3.9 |
| Not administered | 2 | 1.7 | Not administered | 4 | 7.8 |

One of the treatment recommendations from the NHLBI, 2002 is the appropriate assessment and intervention of potassium repletion based on blood chemistry analyses. Of the 168 medical records reviewed which included 117 inpatient and 51 observation encounters there was a very small percentage of encounters with recorded potassium repletion, which was appropriate based on serum chemistry results for each encounter within the first 24 hours of either the inpatient admission or observation status encounter. Of the 117-inpatient status encounters there were 105 (89.7%) inpatient encounters without potassium repletion being administered, while 9 (7.7%) did receive intravenous potassium repletion; 3 (2.6%) received 20 milliequivalents (mEq) of potassium and 6 received 40 mEq of potassium. There were 3 (2.6%) inpatient encounters with no documented data. Of the 51 observation status encounters 50 (98%) had no documentation of potassium repletion with 1 (2%) having documentation of potassium repletion of 40 mEq based on laboratory chemistries.

Opioids are one of the main clinical practice cores of pain management in sickle cell disease. The recommendation from the NHLBI (2002) is that “pain management should be aggressive to relieve pain and achieve maximum function expediently.” Severe pain in SCD should be considered a medical emergency which therefore needs prompt and timely treatment:

1. Begin hydration: the initial fluid should be 5% dextrose + half-normal saline with 20 mEq KCL/L adjusted for serum chemistries.
2. Assess the cause of pain and any complications. Determine medications or treatments taken at home, including usual drugs and dosages, and any potential side effects during acute pain. Then use the opioid dosage which provided

adequate analgesia at a previous time engaged in care (for the patients known to a practice with a previous treatment history).

3. Avoid intramuscular injections. However, if unable to obtain intravenous access, the subcutaneous route for administration of opioids is effective and acceptable.
4. Frequent assessments of pain intensity, relief, mood, and sedation level are required every 15 to 30 minutes after each dose of medication.
5. Titration to relief is an important aspect of care, regarding the nature of recurrent pain episodes and for consistent management of acute pain episodes. Titration can be achieved with aggressive dosing and with frequent or close monitoring; bolus dosing should be set at timed intervals after a loading dose, or “by the clock” (BTC) dosing, such as morphine 4 mg every 2 hours.
6. Disposition at the conclusion of treatment must also be considered, whether an individual is being discharged from the ED or from the inpatient setting. Individuals need prescriptions for equivalent doses of pain medication to maintain pain relief. However, after aggressive treatment is given and pain relief is not achieved, inpatient admission should be considered (NHLBI, 2002).

Of the 117 medical records reviewed with inpatient status the standard of care for most commonly used opioid was hydromorphone 99 (84.6%) with morphine 17 (14.5%) and 1 (0.9%) undocumented data. Of note, there was one (0.9%) record with oral administered opioid within the first 24 hours of admission, the documented pain score was “7” and labeled “unacceptable”. The medication documented for treatment was Morphine 30mg immediate release tablets with two, one tablet doses given during the first 24 hours. This was supplemented with “as necessary” (prn) Ultram for 2 doses

during this same 24-hour period. The dosing for both medications was every four hours. There were 2(1.8%) inpatient status encounters with no opioid pain medication being documented for the first 24 hours of the inpatient admission. The first medical record reviewed in which no opioid was given the patient reported pain score was documented as “9/10” and labeled “unacceptable” for the patient. The second medical record reviewed the patient reported pain score was “6/10” and labeled as “acceptable” with the pain level rising to “10/10” and being changed to “unacceptable” with no opioid medication being administered in the first 24 hours of the inpatient admission. There was no documented explanation for the withholding of opioid pain medication in either medical record. Both medical records had documented the use of the non-steroidal anti-inflammatory (NSAID) drug ketorolac at least once for each in the first 2 hours. There were 51 medical records reviewed with observation status. The standard of care for the most commonly used opiate was hydromorphone 45 (88.2%). Table 8 contains frequencies for cases with hydromorphone and morphine administration.

**Table 8.**

**Opioid Medications**

| NHLBI Guidelines | (Inpatient) n=117 | % | (Outpatient) n=51 | % |
|---|---|---|---|---|
| Morphine | 17 | 14.5 | 6 | 11.8 |
| Hydromorphone | 99 | 84.6 | 45 | 88.2 |
| None | 1 | 0.9 | 0 | 0 |

The NHLBI 2002 guideline highly recommends opioid medication administration with the use of patient controlled analgesia (PCA). For the medical records reviewed for this post hoc quality improvement project PCA was the usual route of IV administration. It was noted for the 117 inpatient status records reviewed there were 8 (6.8%) encounters where “bolus dosing” was used with the timing parameters of “every 1-4 hours’ prn”. It was also noted for the 51-observation status medical records reviewed that there were 6 (11.8%) encounters where “bolus dosing” was used with the timing parameters of “every 1-4 hours’ prn”. There was no identifiable documentation for the reasons these individuals were not administered medication using PCA during these hospital encounters.

The utilization of hydromorphone for the management of vaso-occlusive crisis pain episodes was greater in this post hoc medical record review than the use of morphine. To further understand the impact of these medications the contexts of the dosages the morphine equivalents for hydromorphone as compared to morphine were calculated to facilitate an accurate comparison of opioid utilized and administered. This calculation was based of the recommended dosing of the NHLBI (2002). One important difference between morphine and hydromorphone is the potency of the opioids. Dilaudid a synthetic derivative of morphine has been estimated to be as little as one to four times more potent and maximally one to ten times more potent than morphine (Felden et al 2011; Myers-Glower 2013 & Gulur et al 2015). This facility’s pharmacy parameters for the potency of Dilaudid have been utilized on a one to six ratio (Facility Pharmacy, 2010). Of the 117 inpatient medical records reviewed during the first 24 hours of the inpatient admission the opioid mean equianalgesic dose administered for

hydromorphone was 2.68mg (SD ± 3.31), the mean equianalgesic dose administered for morphine was 13.04mg with (SD ± 11.84). Of the 51 observation, medical records reviewed the mean equianalgesic dose administered for hydromorphone was 2.32mg (SD ± 1.81), the equianalgesic dose for administered for morphine was 13.35mg (SD ± 12.13). The range of opioid administered for inpatient encounters during the first 24 hours of the admission was a minimum of 0mg to a maximum 53.33mg of morphine per dose. The mean sum for opioid equivalent doses (both morphine and hydromorphone) administered in the first 24 hours for the inpatient encounters was 1513.26mg. The range of opioid equivalent doses administered for the observation encounters was a minimum of 0.25mg to a maximum 66.66mg as morphine equianalgesic doses. The mean sum for opioid equivalent doses administered in the first 24 hours for the observation encounters was 681.17mg.

One of the methods utilized for the administration of opioids reviewed was patient controlled analgesia (PCA). This study evaluated the number of doses that were attempted hourly and the number of doses that were actually given hourly during the first 24 hours of inpatient and the first 24 hours of observation status care for adults admitted with a sickle cell pain episode to current guidelines of the NHLBI. There were 105 inpatient encounters reviewed with 12 encounters with no documented data. For PCA injects attempted hourly the range was 0 to 44 attempts M=7.19 (SD ± 6.26). For this same group the number of PCA injects delivered hourly range was 0 to 15 M=5.26 (SD ± 3.55). There were 43 observation encounters reviewed with 8 encounters with no documented data. For PCA injects attempted hourly the range was 0 to 26 attempts

M=6.44 (SD ± 5.98). For PCA injects delivered hourly for observation encounters the range was 0 to 14 delivered hourly M= 4.39 (SD ± 3.37).

Rapid titration to pain relief is one of the recommendations of the NHLBI for the treatment of the sickle cell individual experiencing vaso-occlusive pain episode to make the pain more tolerable and manageable while being hospitalized. It was noted that at the facility all individuals being treated for VOC of sickle cell disease with continuous dosing of an opioid for pain management or basal rate dosing, per hospital policy, allowed for hourly increasing or up titration for pain (Facility policy, 2000). This titration allows the nursing staff to assess and modestly increase opioid medications based on patient reporting of pain and symptoms. This policy was adopted in congruence with the NHLBI 2002 treatment recommendations. However, of the 117 inpatient encounters reviewed, seven inpatient encounters were missing data and 103 (88%) encounters had no increase or up titration during the first 24 hours of admission. Only 7(6%) of the inpatient encounters had titration changes noted with only 2 (1.71%) of those changes being increases in opioid. For the 51 observation encounters reviewed with three observation encounters with missing data 46 (90.2%) encounters had no increase or up titration during the first 24 hours of admission. Only 2 (3.9%) had up titration changes noted during the first 24 hours of admission.

The use of non-steroidal inflammatory medications (NSAIDS) is strongly recommended by the NHLBI during the first 24 hours of inpatient and the first 24 hours of observation status care for adults admitted with a sickle cell pain episode. Of the 117 inpatient medical records reviewed the use of non-steroidal anti-inflammatory medications (NSAIDS) were used primarily for an indication of pain as noted for 72

(61.5%) inpatient encounters with 45 (38.5%) inpatient encounters with no documented data. The number of NSAIDS doses given ranged from 1 dose to 4 doses, M = 2.07 (SD ± 0.86). For the inpatient medical records reviewed the most commonly used NSAID was ketorolac and route of administration are described in Table 9. Of the 51 observation, medical records reviewed the use of non-steroidal anti-inflammatory medications (NSAIDS) were used primarily for an indication of pain as noted for 23 (45.1%) medical records with 28 (54.9%) medical records with no documented NSAID administration. The number of NSAIDS doses given ranged from 1 to 4 doses on average with M = 1.87 (SD ± 1.01). For the observation encounters the most commonly used NSAID was ketorolac and route of administration is described in Table 9.

**Table 9.**

**Non-Steroidal Anti-inflammatory Drugs**

| NSAIDS | Dosage | Interval | (Inpt) n | % | (Outpt) n | % |
|---|---|---|---|---|---|---|
| Ketorolac | 15mg-30mg | Every 6 hours | 72 | 100 | 24 | 100 |
| Ibuprofen | 400mg-800mg | Every 4-6 hours | 0 | 0 | 0 | 0 |
| Naprosyn | 500mg | Every 12 hours | 0 | 0 | 0 | 0 |

| Route | (Inpatient) n | % | Outpt)n | % |
|---|---|---|---|---|
| IV | 67 | 93.1 | 22 | 95.7 |
| Oral | 5 | 6.9 | 1 | 4.3 |
| No documented data | 45 | 0 | 28 | 0 |

| Doses Administered | (Inpt) n | % | (Outpt) n | % |
|---|---|---|---|---|
| 1 | 21 | 29.2 | 11 | 47.8 |
| 2 | 31 | 43.1 | 6 | 26.1 |
| 3 | 16 | 22.2 | 4 | 17.4 |
| 4 | 4 | 5.5 | 2 | 8.7 |
| No documented data | 45 | 0 | 28 | 0 |

The use of adjuvants is also strongly recommended by the NHLBI during the first 24 hours of inpatient and the first 24 hours of observation status care for adults admitted with a sickle cell pain episode. Of the 117 inpatient medical records reviewed, adjuvants were used to help manage symptoms related to pain management such as opioid induced pruritus and nausea. The indications are described in Table 10 as noted for 76 medical records reviewed and 41 records with no documented data. The number of adjuvant doses given ranged from one to nine doses, M = 1.80 (SD ± 2.95). Of the 51 observation, medical records reviewed, 23 had no documented data. Their

indications are described in Tables 10 and 11 respectively. The range of adjuvant doses given was from one to ten doses on average with M=1.93 (SD ± 3.34). Adjuvant administration is described in Table 10 (Inpatient encounters) and Table 11 (Observation encounters).

**Table 10.**

**Inpatient Adjuvants**

| Adjuvants | Dosage | Interval | n | percentage | Indication | n | (%) |
|---|---|---|---|---|---|---|---|
| Benadryl | 25mg-50mg | 4-6 hours | 45 | 59.2 | Pruritus | 44 | 57.9 |
| Atarax | 25mg | 4-6 hours | 1 | 1.3 | Pruritus | 1 | 1.3 |
| Zofran | 4mg-8mg | 4-6 hours | 16 | 21.1 | Nausea | 16 | 21.1 |
| Baclofen | 10mg | 8 hours | 2 | 2.6 | Spasms | 2 | 2.6 |
| Lyrica | 50mg-600mg | 12 hours | 4 | 5.3 | Pain | 4 | 5.1 |
| Neurontin | 100mg-900mg | 8-12 hours | 3 | 3.9 | Pain | 3 | 4.1 |
| Ativan | 0.25mg-1mg | 6-12 hours | 5 | 6.6 | Anxiety | 6 | 7.9 |
| No documented data | | | 41 | | | 66 | |

| **Route** | **n** | **Percentage** |
|---|---|---|
| IV | 19 | 24.7 |
| Oral | 58 | 75.3 |
| No documented data | 40 | |

| **Number of Doses Administered** | **n** | **Percentage** |
|---|---|---|
| 1 | 29 | 39.2 |
| 2 | 21 | 28.2 |
| 3 | 9 | 12.2 |
| 4 | 7 | 9.5 |
| 5 | 3 | 4.1 |
| 6 | 4 | 5.4 |
| 7 | 1 | 1.4 |
| No documented doses | 43 | |

**Table 11.**

**Observation Adjuvants**

| Adjuvants | Dosage | Interval | n | (%) | Indication | n | (%) |
|---|---|---|---|---|---|---|---|
| Benadryl | 25mg-50mg | 4-6 hours | 17 | 60.7 | Pruritus | 17 | 60.7 |
| Atarax | 25mg | 4-6 hours | 1 | 3.6 | Pruritus | 0 | 0 |
| Zofran | 4mg-8mg | 4-6 hours | 5 | 17.9 | Nausea | 5 | 17.9 |
| Baclofen | 10mg | 8 hours | 0 | 0 | Spasms | 0 | 0 |
| Lyrica | 50mg-600mg | 12 hours | 1 | 3.6 | Pain | 1 | 3.5 |
| Neurontin | 100mg-900mg | 8-12 hours | 1 | 3.6 | Pain | 1 | 3.5 |
| Ativan | 0.25mg-1mg | 6-12 hours | 3 | 10.6 | Anxiety | 4 | 14.4 |
| No documented doses | | | 23 | | | 23 | |

| **Route** | **n** | **Percentage** |
|---|---|---|
| IV | 8 | 28.6 |
| Oral | 20 | 71.4 |
| No documented data | 23 | |

| **Number of Doses Administered** | **n** | **Percentage** |
|---|---|---|
| 1 | 10 | 35.7 |
| 2 | 13 | 46.4 |
| 3 | 3 | 10.7 |
| 4 | 0 | 0 |
| 5 | 1 | 3.6 |
| 6 | 0 | 0 |
| 7 | 1 | 3.6 |
| No documented doses | 43 | |

## Summary of chapter

The NHLBI guidelines comparison to determine clinical patterns during the first 24 hours of the inpatient admission clearly determined clinical practice pattern deficits in these dashboard measures: patient assessments, utilization of intravenous fluids, oxygen administration, and choice of pain medications including opioids, NSAIDS, and other adjuvants. Deficits were found for IV hydration and the selection of the recommended fluid, the titration of opioid medications to pain relief and inclusion of patient desired pain goals for the treatment of vaso-occlusive pain treatment during the first 24 hours of hospitalization regardless of inpatient or observation status.

# Chapter Five

# Discussion

## Oxygenation, Pain Intensity Scores, and Patient Pain Goals

The results of this post hoc medical review indicated that the health center nursing providers had a high rate of adherence with taking and recording vital signs for individual patients. Of the 168 encounters reviewed, 90% of the patients had vital signs done every four hours which is a reasonable expectation for general care (NHLBI, 2002). The results from this post-hoc medical record reviewed were divided into two categories. The first category was a representation of the inpatient status for medical records with 117 encounters and the second category was a representation of the observation status with 51 encounters.

For this project study period the recording of oxygen saturation rates were very consistent for both the inpatient and observation status encounters. With the average oxygenation status maintained above 90% as recommended by the NHLBI 2002 guidelines for treatment. It was unclear if oxygen was used because of low oxygenations rates or if oxygen was placed as comfort for those individuals that consider oxygen as “necessary” to aid in the alleviation of pain. The facility implemented a policy in January 2010 “*sickle patients that need treatment with continuous dosing of an opioid and or basal rate are required to be maintained on continuous capnography for oxygenation monitoring congruently with treatment*.” Limited literature is available regarding the implementation of capnography therapy, specifically for the individual with sickle cell disease for continuous opioid

administration. The Anesthesia Department of the hospital determined this additional step was warranted as a safety mechanism to guard for over sedation, while traditional use of capnography in sickle cell patients has been utilized in other instances, such as the management of acute chest syndrome- a life threatening complication, or for a patient that is in the intensive care hospital setting. In this instance the use of the Dartmouth Microsystem could help to establish evidence based parameters for the implementation for continuous capnography in the setting of continuous opioid or basal rate administration (Dartmouth Clinical Microsystem, 2005). The Dartmouth Microsystem could help to determine the overall process for the use of capnography and help to clearly identify the purposes for said therapy by focusing on patient safety and the possible reduction of over sedation. The use of capnography with continuous opioid use for the management of vaso-occlusive crisis events of the hospitalized patient could become more widespread thus helping to alleviate provider fears regarding the administration of opioids and in some cases the high doses that are required for the non-naïve opiate individual. This could be evaluated by the incidence of the hospitalized sickle cell individual and the occurrence of over sedation events while utilizing capnography therapy, thus, helping to establish improved care, enhanced safety, and new evidence for creating clinical patterns of pain management.

One major limitation with the use of capnography for the measurement of oxygenation is the non-existence of any previous literature or data available specifically for sickle cell disease vaso-occlusive crisis pain management. The facilities' health program is currently demonstrating in real time the benefit of this modality as a tool in the management of pain with continuous dosing patient controlled analgesia.

According to the data from this project the assessment and evaluation of pain for the sickle cell disease adult hospitalized experiencing vaso-occlusive crisis pain the mean intensity of pain for the inpatient encounters reviewed was 7.48 (SD±1.89) out of 10 and for observation encounters reviewed the mean pain intensity level was 7.92 (SD±1.48) out of 10. Most of the available literature discusses pain either in the outpatient setting which includes home or the emergency department. There is limited research that addresses the pain of the hospitalized adult whether inpatient or observation status which is a significant limitation specifically regarding titration and pain improvement. The presence of pain was acknowledged and consistently recorded for both settings. The “failure” for pain management in this study is directly tied to the very rare instances of up titration to alleviate pain. The continuous dosing of pain medications as written by the hospital policy (2000) allows for modest increases based on pain intensity scores. For the medical records reviewed for inpatient management only 7 (6%) of the inpatients and 2 (3.9%) of the observation population had titration changes with only two of those changes being increased medications for improving pain relief.

The implementation of the Dartmouth Microsystem (2005) processes would be utilized to reinforce and educate the nursing providers to execute established practices and utilize processes that have been placed specifically to improve patient care, and clinical practice. The Microsystem could be utilized to change the process if needed but the evidence from the available data identified the process for opioid titration has not been utilized as intended and needs to be addressed. The education for all care providers regarding this policy could lead to improved overall pain intensity scores with

an increase of titration for treatment in a timely manner as recommended by the NHLBI, 2002 guidelines.

This information poses an opportunity for future studies to explore and implement clinical practices that incorporate pain management guidelines that assist the provider (physician or advanced practice providers) to alleviate pain with titration recommendations written into the orders, assist the nurses to titrate according to the orders based on the pain intensity levels, provide patient safety, reduce complications from prolonged pain events, and increase administration of pain relieving medications, which is ultimately more patient centered care and a higher quality of care. The implementation of orders sets and sickle cell specific protocols for the management of sickle cell vaso-occlusive crises pain has been recommended to promote higher quality care and improve clinical practice patterns (Lottenberg & Hassell, 2005; Ballas, 2010; Frei-Jones, Field, & DeBaun, 2009).

Patient reported pain goals, a critical part of the pain management assessment for both the inpatient and observation encounters as identified in this study, had two notable components. The first finding indicated for 52.1% of inpatient encounters and 60.8% of observation encounters no data were documented for patient pain goals. Patient desired pain goals should be required to guide patient specific treatment. Lack of patient pain goals can unintentionally create underutilization of needed opioids. This can also be considered dismissive of the patients' pain perception, which further adds to the distrust between patients and providers (Ballas, 2010) which can lead to ineffective treatment and prolonged pain. Successful strategies could be implemented with the guidance of the Dartmouth Microsystem as a framework with the incorporation

of this needed assessment information to guide clinical practice for improved and optimal pain management. The NHLBI 2002, recommendations for rapid titration and inclusion of previously successfully implemented treatment support the need for obtaining this information. According to Ballas, 2005, “the patient’s self-report (of pain) is the most important factor in the hierarchy of pain management.” The lack of this crucial information can be akin to the rendering of suboptimal care and disbelief of the patient’s pain experience.

A second finding for the patient reported pain goals was that many patients recorded acceptable levels of pain less than their desired pain goals. This may require some education on the part of the individual patient to understand the differences between an acceptable level of pain and what a desired level of pain actually means. Of the 117 inpatient encounters reviewed for pain goals during the first 24 hours of the admission 56 (47%) records recorded patient reported pain goals as M=3.0 (SD ± 2.19). Of the 51 observation status encounters reviewed for pain goals during the first 24 hours of the admission 20 (37%) records with patient reported pain goals were M=2.5 (SD ± 2.37). With the facility moving towards the implementation of the electronic health record called Epic by the year 2018 improving this process of determining patient pain goals could be “created as part one of the critical elements for care during the Epic build and followed as part of the quality improvement dashboard for improving clinical practice patterns. This would enable the recording of patient reported goals “hardwired” as the one of the new standards for care. The creation of an electronic template which may include “soft stops”-answer this question to continue and/or “hard stops” you cannot move past this point without inputting information, can

directly improve the opportunity to meet patient expressed pain goals. This would improve overall pain management and clinical practice patterns based on the subjective needs of individuals being treated for vaso-occlusive pain while hospitalized as recommended by the NHLBI 2002 guidelines. This will also allow the clinical care team more concrete information to assist in the process of ordering and titrating opioids to give the patient optimal analgesia.

**Intravenous Fluids and Intravenous Rates**

The recommended intravenous fluid to promote optimal hydration and reduce the sickling viscosity of blood per the NHLBI 2002 guidelines is five percent dextrose and half-normal saline. These data present an opportunity to educate care providers regarding the utilization of hypotonic solutions such as five percent dextrose and half-normal saline is useful because free water enters the hypertonic red blood cells, leading to a decreased hemoglobin concentration (MCHC) and reduced red blood cell sickling (Gavrillis & Rothenberg, 1973 & Bunn, 1997). Intravenous fluids should be infused to correct deficits and promote euvolemic states with adequate, fluid, and rates.

The recommended intravenous fluids rates per the NHLBI 2002 guidelines should not exceed “1.5 times maintenance (including volume for drug infusions).” For this study the inpatient encounters IVF rate 69 (59.0 %) were less than the recommended 1.5 times the maintenance rate for IVF, none were determined to exceed the 1.5 maintenance rate with 2 encounters of no documented data. For the observation encounters 24 (47.1%) were less than the recommended 1.5 times the maintenance rate for IVF, 2 (3.9%) was determined to exceed the 1.5 maintenance rate and 4 (7.8%)

encounters of no documented data. The NHLBI 2002 stresses the importance of adequate hydration to prevent further dehydration and promote euvolemic states in individuals experiencing vaso-occlusive pain crisis. Hydration status for individuals in crises is an important aspect of care the affects the pathophysiologic of sickling and dependent on clinical practice to promote hemostasis by utilizing IVF as part of the current clinical practices of the hospitalized adult (Ballas, 2010 & Yale et al. 2000). The recommended maintenance dose is 2-3 liters per day (Odesina 2001;SCIC 2005;Moritz & Ayus 2015; Okomo & Meremiku 2015).

While discussing intravenous hydration potassium repletion is also recommended by the NHLBI 2002 guidelines. There were a very small percentage of encounters with recorded potassium repletion within the first 24 hours of either the inpatient admission or observation status encounter. Of the 117 inpatient status encounters 105 (89.7%) had no documentation of potassium repletion with 3 (2.6%) having no documented data. Of the 51 observation status encounters 50 (98%) had no documentation of potassium repletion with 1 (2%) having documentation of potassium repletion based on laboratory chemistries. Little information regarding importance of potassium repletion was noted in the literature although it was also discussed in the 1999, American Pain Society guidelines for sickle cell pain management. Hypokalemia is a clinical manifestation that may accompany sickle cell vaso-occlusive crisis as either an acute kidney injury or cardiac dysrhythmia and should be carefully evaluated for everyone during a vaso-occlusive crisis pain event (Jaitly et al. 2008; Epstein, 2008). This is a limitation for this study and can be addressed in future studies.

The Dartmouth Microsystem could be utilized to educate and monitor clinical practice changes to ensure implementation of the recommended intravenous fluids and the proper intravenous fluid rates are administer to optimize adequate hydration when the adult is not able to ingest sufficient fluids. The incorporation of the “4-2-1” rule for IVF could assist in determining the correct rates for administration of fluids based on an individual’s weight, which has been obtained upon admission, this can further be established with the creation of sickle cell specific protocols and order sets (Ballas, 2010; Lottenberg & Hassell, 2005; Yale et al, 2000).

**Opioid Utilization**

Opioids are one of the main clinical practice cores of pain management in sickle cell disease. The NHLBI, 2002 guideline recommendations can help direct treatment and help to improve the overall success of clinical practice in managing acute pain.

The guideline recommendations (excerpt):

> *Assess the cause of pain and any complications. Determine medications or treatments taken at home, including usual drugs and dosages, and any potential side effects during acute pain. Then use the opioid dosage which provided adequate analgesia at a previous time engaged in care (for the patient which is known to a practice with a previous history of treatment). Avoid intramuscular injections. However, if unable to obtain intravenous access, the subcutaneous route for administration of opioids is effective and acceptable. Frequent assessments of pain intensity, relief, mood, and sedation level are required every 15 to 30 minutes after each dose of medication. Titration to relief is an important*

*aspect of care, regarding the nature of recurrent pain episodes and for consistent management of acute pain episodes. Titration can be achieved with aggressive dosing and with frequent or close monitoring; bolus dosing should be set at timed intervals after a loading dose, or "by the clock" (BTC-by the clock) dosing, such as morphine 4 mg every 2 hours (NHLBI, 2002).*

For this project, the most commonly utilized opioid for the inpatient encounters was hydromorphone 99 (84.6%), with morphine 17 (14.5%) for 117 inpatient status encounters. For the observation status encounters the opioids were utilized as follows hydromorphone 45 (88.2%) with morphine 6 (11.8%), for 51 observation encounters. Most encounters of the hospitalized adult for the treatment of vaso-occlusive crisis pain received some form of opioid to treat acute pain as recommended. There was however one (0.9%) where the opioid was administered orally. There was no documentation why the route was not intravenous. There also were two inpatient encounters where no opioid was administered in the first 24 hours and no documentation was available to support this practice for the two encounters, which did not follow the treatment recommendations for the NHLBI guidelines that opioid be given intravenous (Ballas, 2010; Lottenberg & Hassell 2005; Frei-Jones et al, 2009).

The under medicating of individuals that present for vaso-occlusive crisis pain with the use of opioids can be directly related to provider bias and mistrust (Ballas, 2010 & Frei-Jones et al, 2009) this issue is not unique to the hospital but to the sickle cell community in general. This systemic problem needs to be addressed more succinctly across the many avenues individuals with sickle cell disease may reach out to for assistance in the management of VOC. The aid the sickle patient would require is to

receive proper doses of medication, rapid treatment, rapid assessment, with titration of opioids to adequately address pain (NHLBI, 2002). The Dartmouth Microsystem (2005) can help with improving systems that can create evidenced based practices initiated from medical record information, previous successful treatments, hematological input, and help to eliminate provider mistrust (Dartmouth Microsystem 2005; Ballas 2010; & Frei-Jones, Field, & DeBaun, 2009). This provider bias and mistrust does not exist in pediatric sickle cell care and management which allows for comprehensive care, trusting provider and patient relationships and interactions, which translates to high quality sickle cell care (Ballas, 2010; Frei-Jones et al, 2009), which improves rapid treatment and provides for improved opioid management during a sickle cell vaso-occlusive pain event.

This project also reviewed equianalgesic dosing for opioids administered during pain treatment of the hospitalized adult during the first 24 hours, this dosing was based on calculations for treatment as recommended by the NHLBI 2002 guidelines noting hydromorphone's potency is 6 times greater than morphine (Felden et al 2011; Myers-Glower 2013 & Gulur et al 2015; Facility Pharmacy, 2010). For the inpatient encounters for hydromorphone the M = 2.68mg (SD ± 3.31), for morphine the M = 13.04mg (SD ± 11.84). For the observation encounters for hydromorphone the M = 2.32mg (SD ± 1.81), for morphine the M = 13.35mg (SD ± 12.13). Generally, opioids were administered by using the recommended vehicle the use of PCA-patient controlled analgesia over bolus dosing or oral administration. The opioids administered were usually under-dosed for the management of patient pain as evidenced by documented

self-reported high level pain scores and continued reports of unacceptable levels of pain with opioid administration.

This study also reviewed data which observed how the PCA was utilized during the first 24 hours of the adult patient admission. For 105 (89.7%) of the inpatient encounters with 12 (10.3%) undocumented encounters data, the number of PCA injects attempted hourly M = 7.19 (SD ± 6.26) with a range of 0 to 44 attempted injects per hour. The number of PCA injects delivered for this same group was M =5.26 (SD ± 3.55) with a range of 0 to 15 injects delivered hourly. For 43 (84.3%) of the observation encounters with 8 (15.7%) undocumented encountered data, the number of PCA injects attempted hourly M = 6.44 (SD ± 5.98) with a range of 0 to 26 attempted injects per hour. The number of PCA injects delivered for this same group was M = 4.39 (SD ± 3.37). Solomon, 2010 suggests that opioid administration should be dependent on previous analgesic dosing and consider weight based dosing as recommended by the NHLBI 2002. Several studies agree the baseline for treatment with opioids should begin with the last previous efficacious dose if the individual in known to a practice of facility (Ballas, 2009; Solomon, 2010, NHLBI 2002). Given the range and number of doses attempted for both populations the recommendation of the NHLBI to titrate to relief needs to be incorporated into any treatment regimen to improve the alleviation of pain and the efficacy of opioid treatments. This is further evidence that the doses for opioid given were generally seen to be less than required to provide analgesia or adequate pain relief.

The increasing or up titration of opioid treatments was rarely observed in the data collection of this post hoc medical record review. The hospital has included in the order

set for PCA dosing the parameters for modestly increasing the opioid dose for an individual in vaso-occlusive crisis pain hourly based on the patient report of pain and symptoms. For the inpatient encounters 103 (88%) had no increase or change in titration noted with 7 (6%) with no documented data and 7 (6%) with titration changes but only 2 (1.7%) were increases in opioid to manage pain. For the observation encounters 46 (90.2%) had not increase or change in titration noted with 3 (5.8%) with no documented data and 2 (3.9%) had increases or up titration to manage pain.

One possible conclusion for nurses not implementing the ability to titrate opioid pain medications modestly as the policy is written are the nurses concerns for over sedation, respiratory depression, and the inability to properly assess patients in a hectic environment of inpatient and observation hospital care along with provider bias regarding patients reporting of pain (Bernhofer, 2011). The ability to eliminate personal bias and judgments while providing care will allow optimal clinical practice, improved overall pain management, and increase patient satisfaction with hospital pain management (Dupree et al, 2009; Bernhofer, 2011, Ballas, 2010, NHLBI 2002). These processes are not intended to discount nursing concerns for patient safety. Educating and removing the emotionality from the process of using opioid medications especially with the ability to modestly titrate the opioid pain medications will allow for the provision for safe, appropriate, and humane care while providing adequate analgesia (Bernhofer, 2011 & Dupree et al, 2009). The nurse can and should practice with the autonomy the hospital titration policy allows for to address adequate analgesia needs, and feel comfortable with the added dimensions that will be included in the electronic medical record as reminders of care that add to clinical practice and safety. The recruitment of

more providers trained to manage sickle cell disease could be very impactful in the adult population which would aid to decrease provider bias.

The use of the Dartmouth Microsystem (2005) should guide the pain management quality improvement processes and measure the implementation and effectiveness of the system changes. The NHLBI 2002 and the hospital 2000 treatment protocol is already in place. The providers should be educated to use the tools in place to titrate appropriately to alleviate pain. The facility policy can be reintroduced to the care providers to optimize the nurses' role to increase the medications based on the assessment of the patient and within the ordered parameters for the individual on PCA continuous dosing. The clinical practice patterns can be reevaluated in set time frames to ensure the clinical processes positively impact the improvement of pain and the overall patient reported pain scores and acceptable levels of pain. This will allow the implementation of the recommended NHLBI 2002 as utilized by the facility to place into practice the specific clinical practices by use of the EPIC EHR system to expand the improvement of pain management during the first 24 hours of the inpatient hospitalization. The inclusion or possible revision of protocols specific for sickle cell disease management can again improve the speed of titration and quality of pain management clinical practice patterns. This can be implemented with the introduction of EPIC electronic health record (EHR) system in 2018, by creating sickle cell specific templates that directly address opioid administration and the frequency of monitoring during treatment. The nursing assessments created should specifically entail nursing concerns with sedation levels, respiratory status, alertness, and for the patient i.e. pain

goals, acceptable level of pain, location of pain, and patient satisfaction with care (Dartmouth Microsystem, 2005 & Bernhofer, 2011).

**NSAID and Adjuvant Utilization**

The management of pain as recommended by the NHLBI 2002 should include NSAID and adjuvants to enhance opioid use if indicated. The use of NSAIDS in this study was primarily for the indication of pain. The most commonly used NSAID being ketorolac for both populations. The most frequently used route for administration was intravenously. The role of anti-inflammatory medications in the management of vaso-occlusive crisis has two main functions-to help reduce the inflammation present because of the underlying sickle cell disease and to work synergistically with opioids to bring pain relief (APS, 1999 & NHLBI 2002).

According to the data from this study for the inpatient encounters the use of NSAIDS was utilized for more than half of those treated for pain while in the observation arm less than half were administered an NSAID. For both populations, there were thirty percent or more with no documented data for this parameter of NSAID use. Given the large percentage of undocumented data for the use on NSAIDS this has proved to be a limitation of the project. This project showed only modest use of NSAIDS and adjuvant therapies for the management of pain and the reduction of pain management induced symptoms. Either the providers are unaware of the clinical benefit the reduction of inflammation and the synergistic effect to enhance analgesia will provide or the clinical care providers need further education regarding the benefit of this class of medications for the use of sickle cell patients. Given the clinical benefit for

this patient population it would be prudent to provide the basic education needed to allow this practice to become part of the standard of care. With the impending EHR this medication can be one of the staples for the order set or template for pain management of the sickle patient regardless of admission status.

The use of adjuvants was primarily for symptomatic complaints such as opioid induced pruritus or nausea. For both populations, the adjuvants were primarily administered orally with more than fifty percent requiring medications to help combat opioid induced pruritus. The use of adjuvant also had a large number of undocumented data for both the inpatient and observation encounters. The most commonly prescribed adjuvants were Benadryl and Zofran, and were proven to be effective as administered orally. For the sickle cell patient that is receiving treatment for vaso-occlusive crisis episode pain the anticipation of pruritus and nausea could bring the added benefit of relief of unwanted symptoms while anticipating the relief of pain. The “hardwiring” of these medications into a sickle cell specific order set would impact clinical practice patterns positively and increase patient satisfaction with hospital care. This was not congruent with several recommendations for treatment in sickle cell specific guidelines (Ballas, 1995; NHLBI, 2002; Rees et al, 2001). Particularly the use of ketorolac has been shown to decrease the need for utilization of opioids and enhance vaso-occlusive crisis pain management for the sickle cell patient.

**Limitations**

There were limitations to this quality improvement project. This project was limited to a small university health center with a relatively small patient sample size. The

design for a quality improvement project was a retrospective post hoc medical record review for a period of one full year January 1, 2014 thru December 31, 2014. The sample for medical review had multiple encounters for several medical records. During the data collection phase, it was noted several encounters had been admitted first as observation and then later converted to an inpatient admission. This was addressed by separating the different admission statuses and evaluating them separately. Patients that had inpatient care should have improved outcomes from patients being cared for 23 hour, inpatient data would be more conservative regarding deficits. However, the data for both patient populations had similar outcomes and deficits despite the intervention of 23 hours of ongoing treatment prior to admission. The instrument used for data collection was created specifically for this quality improvement project. The instrument was modified to incorporate more data and may need to the updated and generalized for replication for other area studies.

The age of the data could be considered a limitation of this project. The data was abstracted for the year 2014. Although several institutional changes were made since the data were collected inpatient care managed by the inpatient team has remained unchanged, and therefore unlikely to impact data relevance. The data was collected by the student investigator who was also an employee of the hospital. The potential for bias during data collection is counterbalanced by the investigator's expertise with the system and institutional practices for sickle cell pain management.

It would be important for future studies to ascertain if oxygen is donned for comfort measures or if truly deemed hypoxic. This determination may prove impactful in other treatment areas and needs to be fully assessed to ensure if underlying pathology is

present it can be fully and appropriately treated. The use of capnography with continuous dosing of intravenous opioids could be a lifesaving measure and needs further evaluation and documentation. The limitation of previously available literature for treatment comparisons creates a unique opportunity to promote this pilot project information to create the opportunity for change and improvement for other treatment facilities by adjusting care parameters for opioid dosing thus increasing the ability for opioid continuous dosing improving pain treatment overall for sickle cell patients.

Pain management for the hospitalized adult in sickle cell vaso-occlusive crisis pain is a limitation and may not be able to generalize to other facilities. However, the different aspects of pain management can be evaluated in other facilities and include: the pain measurement tools, the assessment documentation, and evaluation for the frequency of titration to analgesia-all important aspects of pain management that can be evaluated for improvement. Paramount to this process and a limitation is the inconsistency for determining patient desired pain goals. This information needed to determine analgesia parameters and can be evaluated in other settings to guide the pain protocols and help to create sickle cell specific algorithms to help patients reach improved pain states. This should also include ensuring adequate doses of opioids are administered and titrated for unacceptable levels of pain. Although the hospital policy allowed for modest titration of the opioids based on the patients reported levels of pain it was unclear why this was not carried out. The parameters were clearly listed as part of the medication administration record. Perhaps reeducation may be required to implement options that are available to help improve pain. Lastly, the modest use of NSAIDS and adjuvants could be significantly improved once the reasoning is

determined for the underutilization. This could easily be replicated at other facilities to ensure optimization of available therapies utilized as therapeutically as indicated.

**Implication for Future Studies**

This quality improvement project can be replicated in different facilities across the country to determine their clinical practice patterns for the management of sickle cell disease within multiple settings. The evaluation of key elements can help to determine what areas of practice need improvement and what is being done well that should be sustained. Sickle cell patients reside all over this country and this information is applicable to all who manage individuals living with this chronic debilitating disease. This type of quality improvement project can help to bridge the distress that some providers may have in regard to the self-report of patient pain without the benefit of objective findings for acute pain management.

One of the issues that may be of interest is the use of oxygen. The use of oxygen for many individuals experiencing sickle pain has associated comfort with this practice for pediatric care. This can be addressed by determining true hypoxemia and the clinical need for oxygen versus placating a request because of previous use. This determination could be valuable in future studies regarding clinical practice patterns for oxygenation. The proper intravenous fluid utilized for hydration is another area for clinical practice that can be assessed and evaluated. Unless an individual being treated is deemed to be hypovolemic then the recommendations by the NHLBI 2002 for rehydration should be followed unless contraindicated. Rehydration should include the parameters of fluid rates- “not to exceed 1.5 times maintenance including volume for

drug infusions", along with closely monitoring serum chemistries for hypokalemia and the need for potassium repletion as needed, this was not an issue as indicted with the data collected.

Opioid dosing should be closely evaluated and titrated appropriately to meet the needs of the individual. This should include reviewing patient passports if available, previous successful opioid treatments, and reliable patient reporting where applicable. Under dosing of pain medications should be avoided to prevent untoward complications from prolonged pain events. The use of PCAs as recommended by the NHLBI should be utilized where available. This should also include the frequent assessment of the patients reported pain levels, desired pain goals measurements, and acceptable levels of pain. This should be discussed with the patient at frequent intervals to ensure pain is improving and becoming tolerable for the patient. This should incorporate titrating medications to meet the patient's pain needs versus keeping an individual on the same dose for several days with little to no improvement which causes prolong pain, lengthens the hospital stay, decrease patient satisfaction, and disrupts family and home lives.

Lastly incorporating the use of NSAIDS and adjuvants routinely in specific sickle cell care can help reduce complications associated with opioid pain management i.e. opioid induced pruritus, constipation, and nausea. For some patients being treated with opioids, pruritus can be extremely severe and debilitating to the degree of causing lacerations from scratching with miscellaneous objects. This side effect should not be ignored and may not respond to Benadryl; effective treatments need to be researched and evaluated to decrease the severity of this issue. Treatment with Naloxone has

proven to be effective in some instances but replication of this practice is needed to verify the efficacy of this practice. Nausea should also be treated proactively with the use of strong opioids to prevent further dehydration which can lead to worsening sickling. Oral administration of these medications is preferred however in the presence of active vomiting intravenous route is acceptable. Care providers should encourage adequate nutritional support when appropriate. Evaluating the use of these medications can help establish improved sickle cell specific treatment guidelines and protocols for sickle cell inpatient care with replication of use in multiple settings.

**Implication for Practice**

The clinical practice patterns for this quality improvement project has documented several areas for quality improvement that will be addressed: hydration- the type of intravenous fluids administered, titration of opioids for pain relief, and the recording of patient desired pain goals. Hydration-for this project it was noted the recommended IVF was underutilized five percent dextrose and half-normal saline for more than half of the fluids administered. The use of the correct fluid is crucial for restoring homeostasis and a euvolemic state for the individual experiencing vaso-occlusive crisis pain. Titration for the alleviation of pain – the most important aspect of care for the individual seeking care, rapid titration and the increase of opioid dosing is critical to pain management and needs to happen in a timely manner with the proper assessments for evaluation of treatment. As stated previously titration of opioids for improving pain the hospitalized sickle cell patient for vaso-occlusive pain is critical. For patients reporting high levels of pain in comparison to patient reported desired level for pain and or acceptable pain levels the practice should be to increase the doses and reassessment

until pain has improved. This can be done by giving specific parameters for increasing opioid dosing with nursing assessments and evaluations. Modest increase can be 0.5 to 1mg. hourly to every two hours with frequent assessments especially in the patients that are taking chronic opioids at home. Patient desired pain goals will become the gauge for which pain management is administered and titrated.

**Clinical Dashboard**

The creation of the clinical Dashboard will be completed by the Facilities' Hospital IT Department at the direction of nursing administration and the medical director for the Adult Comprehensive Sickle Cell Program in anticipation of the electronic medical record program Epic 2018. The clinical Dashboard will focus on three outcomes of this quality improvement project which has been presented to the Nursing Administration. The three outcomes of focus:

Hydration: intravenous hydration- to follow the NHLBI recommendation of dextrose five percent with half strength (0.45%) of normal saline, unless active vomiting is noted.

Titration: quickly administering adequate doses of pain medication to help achieve maximal levels of comfort as quickly and safely as possible.

Patient pain goals: the accurate recording of patient reported pain goals to assist with optimal pain relief as guidance for pain management.

A concerted effort on the part of providers will be required to create, implement and monitor the required changes to improve the overall quality of care administered to sickle cell adult patients. The current clinical practice patterns will be transformed to

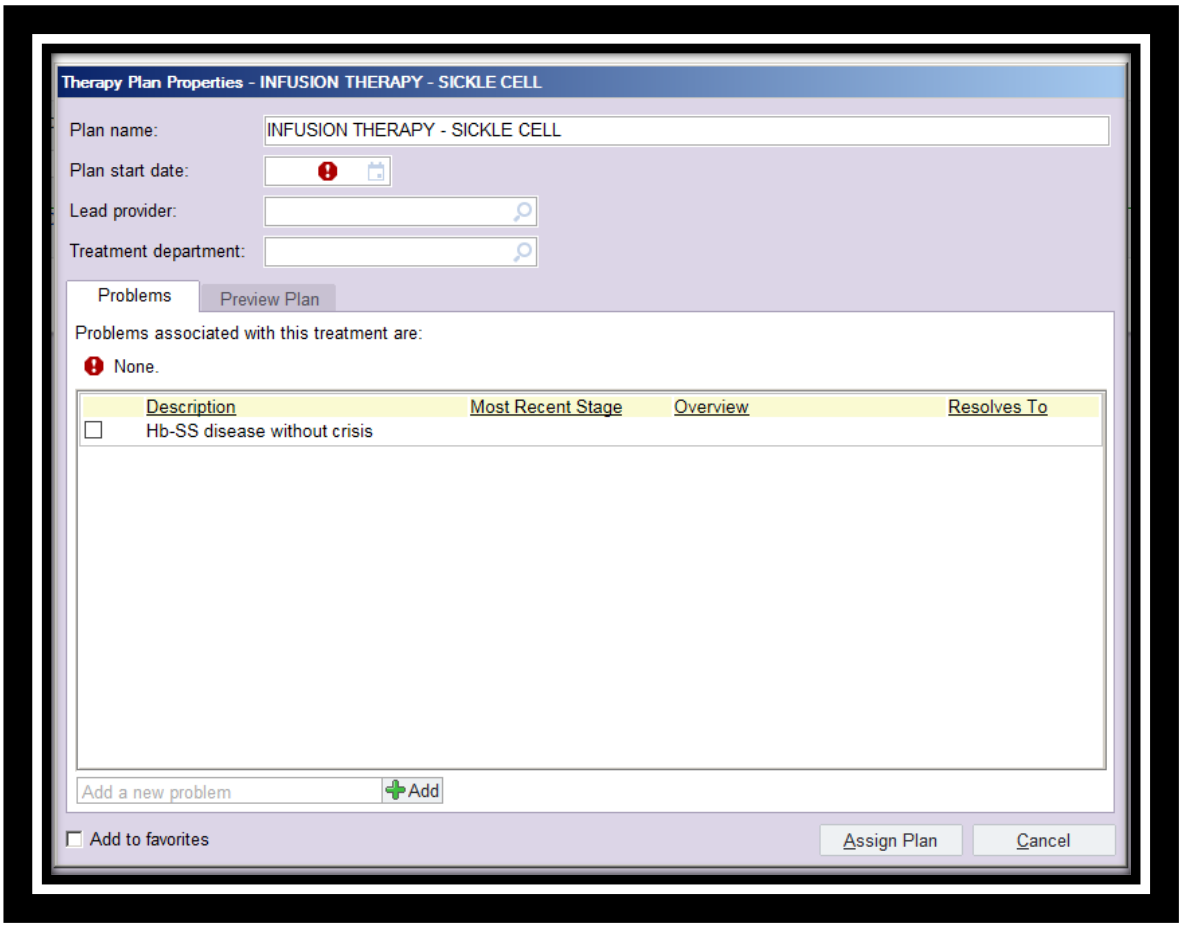
manage patient needs correcting the identified treatment deficits during the first 24 hours of inpatient and the first 24 hours of observation status care for adults admitted with a sickle cell pain episode to current guidelines of the NHLBI for emergency department care utilizing the Dartmouth Microsystem quality improvement initiatives for populating the clinical dashboard.

The clinical dashboard will be based on information extracted from the implementation of the electronic health record EPIC in 2018. The Epic program can be designed to include disease specific order sets that can guide clinical practice. In particular, the order sets for sickle cell disease management can include parameters for intravenous hydration which includes the type of fluid and rate. An example of disease specific sickle cell orders sets is displayed here as Exhibit A.

**Exhibit A. Sickle Cell Infusion Order Set Sample**

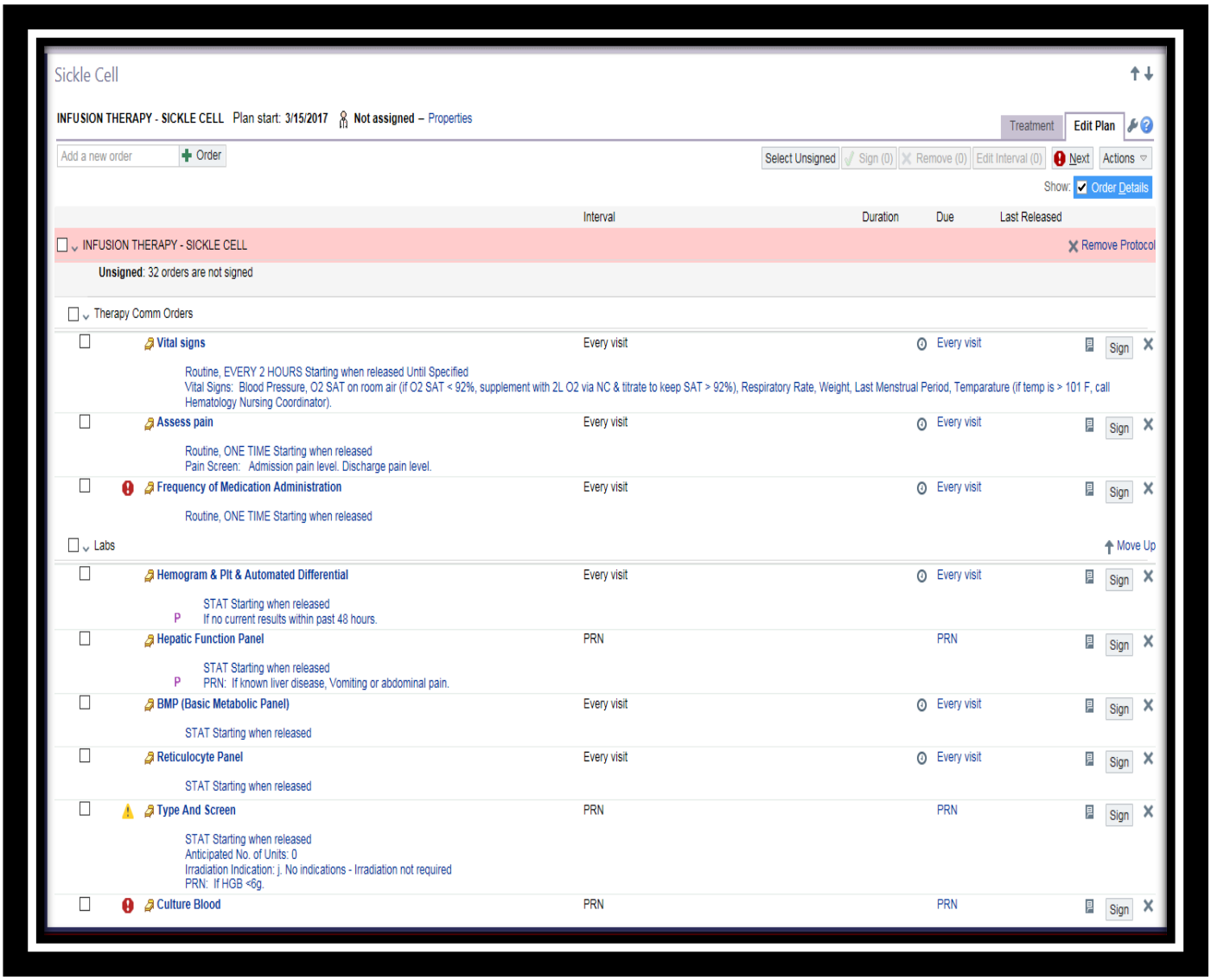

The order set can also include specific parameters for example the outpatient treatment of a vaso-occlusive crisis episode that would be administered in the day hospital a Sickle Cell Infusion as displayed here in Exhibit B.

**Exhibit B. SCD Order Set Sample**



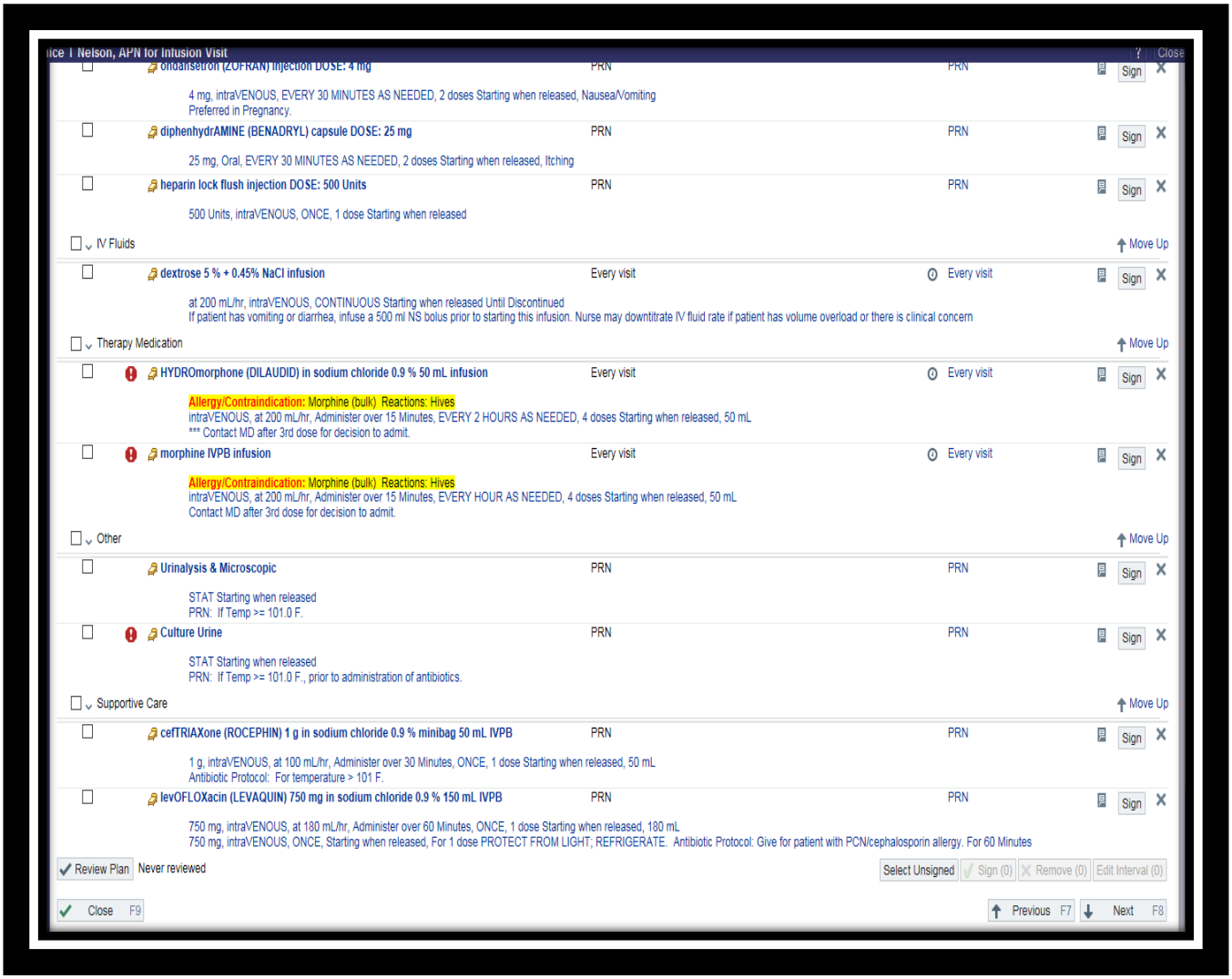

The creation of the Epic design has some unique features that can be capitalized upon for each different facility to cater (attend to the needs of) to unique patient populations. Thus, creating individualized care- creating higher quality clinical practice patterns within disease specific protocols. These order sets can include laboratory requests and orders for the administration of antibiotics if deemed necessary to meet an individual patient's clinical needs, this is displayed here with Exhibits C, D, and E.

## Exhibit C. SCD Order Set Sample A



## Exhibit D. SCD Order Set Sample B

## Exhibit. E SCD Order Set Sample C




With the use of these types of orders sets guiding clinical practice, the monitoring of the clinical practices changes shall be simplified with collaborations between the nursing, medical and IT departments. This would be specifically designed and guided with the Dartmouth Microsystem (2005) with the implementation of the five “Ps.”

The actual clinical dashboard will be created by the healthcare team, patients, IT department, and ancillary stakeholders involved with care for individuals with sickle cell

disease. Cooperatively the clinical dashboard will be created inclusive of the different variables of the Epic electronic medical record. The clinical dashboard will focus on the care being monitored hydration, titration, and patient pain goals. This will aid with the goal of visually observing the achievement of benchmarks towards improving clinical practice and improving the quality of care. The clinical dashboard may look similar to the example displayed here with the appropriately label interventions see Exhibit F.

## Exhibit F. Clinical Dashboard Sample

## Exhibit G. Clinical Dashboard Sample A

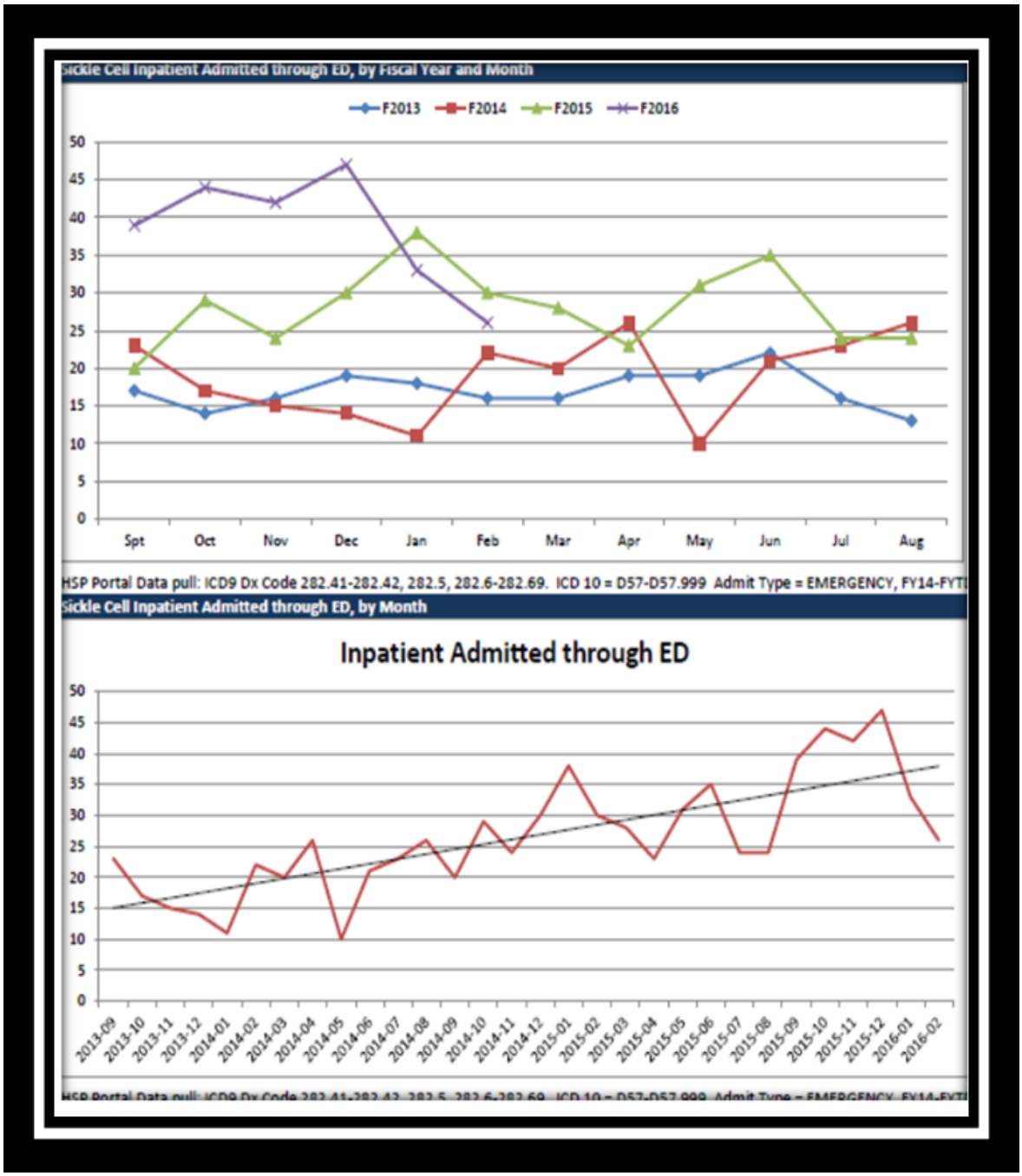
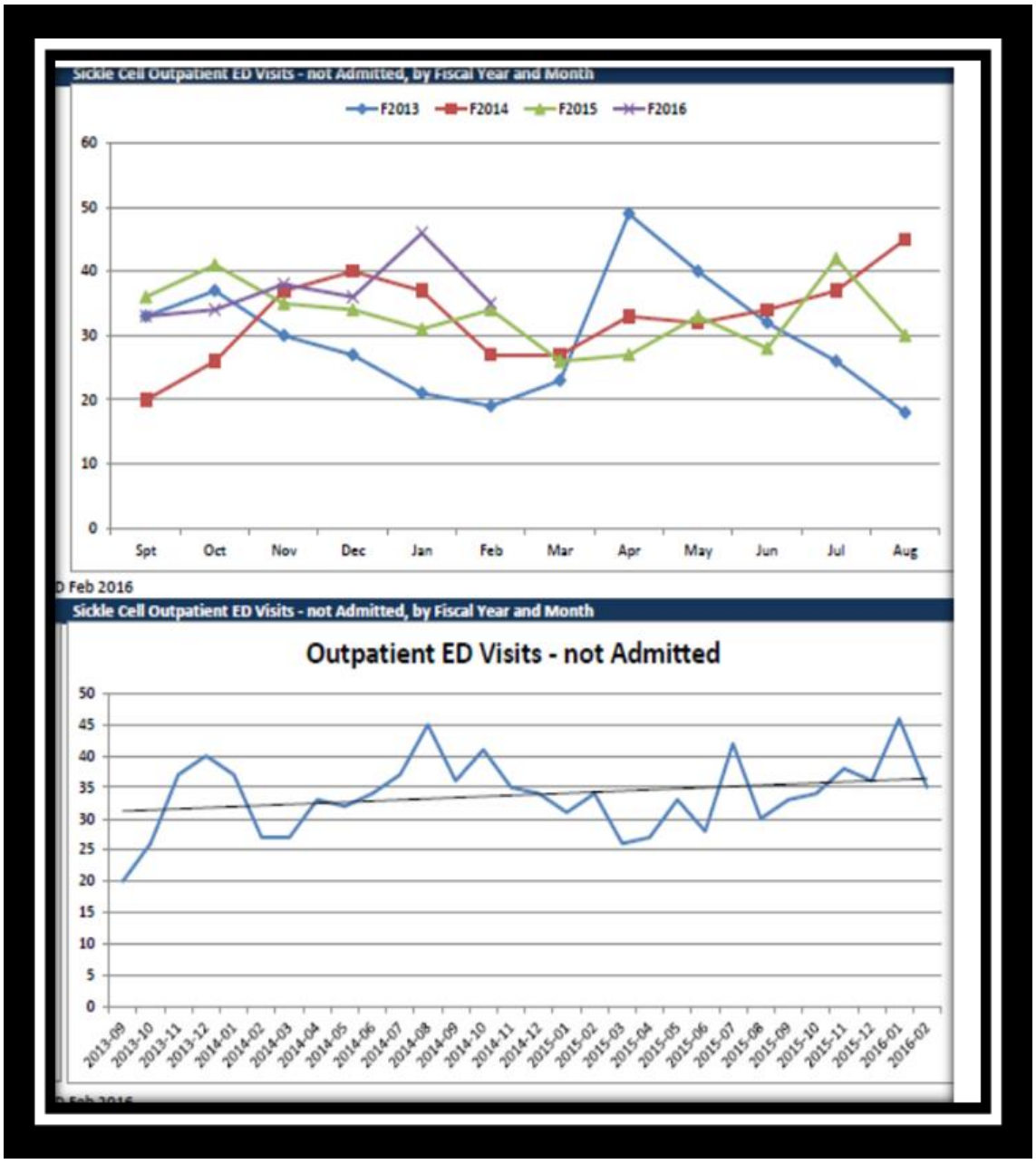


**Exhibit H. Clinical Dashboard Sample B**




The goal for the creation of the clinical dashboard for the hospital will be to provide a clear picture of the care being provided using visualizations as seen in these examples. A dashboard is utilized to convey relevant information to clinicians and leadership in a way that communicates quantitative data that is easily understood. This

aids in the ease of sharing information and correcting deficits. The dashboard also allows for tracking specific measures and clinicians to own where data needs are on track. The dashboard can also allow in an organized manner information regarding financial, operational performance, along with clinical performance which can add to cost saving measures. The metrics to be reviewed: hydration, titration, and patient desired pain goals, to determine if clinical practices changes are being adhered, exchanged- as proficiency develops to improve other clinical practices, updated as benchmarks are met; monitoring all to ensure ongoing high quality improvements and overall care improvements. These are important parameters that should be addressed as part of the Epic build team for the sickle cell disease protocols.

**Implication for Policy**

The hospital has implemented two key policies for the care of sickle cell patient. One of the first being the use of capnography for continuous dosing with opioids by the pharmacy department. This policy could have long reaching implications for policies in other facilities that may consider the use of continuous opioid dosing for sickle cell vaso-occlusive pain as a safety and prevention measure. Determining the impact of this policy in other locations and facilities could globally expand opioid use in pain treatment especially with the negative connotation associated with these medications in the media because of misuse and high profile deaths of superstars like Prince and Michael Jackson.

The second policy allows for modest titration of an administered opioid based on pain levels of the sickle cell patient being treated for vaso-occlusive crisis pain episode.

This policy if followed as ordered allows the nurse to incrementally increase the dose of opioid setting on the PCA to improve analgesia. This increase allows for slowly titrating pain medications with nursing assessments and documentation. This also allows the nurse to titrate down for the patient that has achieved analgesia and is ready to be tapered down on the opioids. These changes in care for patients can be impactful by eliminating wait time for orders and delays in treatment. These policies do not eliminate the need for provider involvement but focus the care on getting pain under control expeditiously. However, this policy has not improved outcomes yet. The implementation and use of these policies will impact positively the quality of care and improve the clinical practice patterns currently in place while improving patient satisfaction with inpatient and observation care. The policies can easily be adopted for use at other facilities and help provide higher quality care for the adult admitted with vaso-occlusive crisis pain. The inclusion of the nursing leadership for the hospital health will help push the initiative to provide high quality care, which will improve trust and satisfaction for both the patient and the provider.

**Implication for Education**

The introduction of the Dartmouth Microsystem will create the opportunity to educate the care providers, especially the nursing staff regarding clinical practice patterns of focus-hydration, titration to pain relief, and patient desired pain goals. The systematic approach will use the 5 P's "purpose-, patients, professional, processes, and patterns. The education will clarify the global aims for the quality improvement project, for the staff (healthcare team) and other stakeholders-whom are patients, IT, social workers, care coordinators, pharmacy and administration , and be evaluated by

the creation of the dashboard with the implementation of the electronic medical record Epic in 2018.

## Conclusion

Sickle cell disease impacts healthcare utilization, families, and individuals living with the disease in a fashion unlike other chronic illnesses. This quality improvement project can have long lasting implications for improved care of the hospitalized adult, creating evidenced based disease specific protocols that can lead to improved pain management. This, in turn, can lead to faster recovery and departure from the hospital. Improving titration to analgesic effect, decreasing hyper-viscosity by administering the correct intravenous fluids at the appropriate rates, and providing adequate opioid management to address each individual desired pain goals will ultimately impact quality of life and function. Having a clinical dashboard to monitor and evaluate overall clinical care patterns allows for corrective action more expediently and applauds the continuance of meeting and exceeding clinical benchmarks visually. This project was undertaken to improve inpatient clinical practice patterns for the hospitalized adult during the first 24 hours of the inpatient admission. With the results and the creation of the clinical dashboard, improvements will be achieved over time including the creation of improved clinical practice patterns and eventually improved outcomes for the adult with sickle cell disease.

## Appendix A

## SCARDS (Sickle Cell Audit Record Data Sheet)

| SICKLE CELL AUDIT RECORD DATA SHEET (SCARDS) | | | |
|---|---|---|---|
| **Medical Record Unique ID#** | | **Date of Audit**: | |
| **Gender**: □ F □ M | | **Age:** | |
| **Race:**<br>☐Black or African American<br>☐Hispanic/Latino<br>☐White<br>☐Unknown | **Ethnicity:**<br>□Jamaican<br>□Haitian<br>□African<br>□Caribbean Islander<br>□Mexican<br>□Puerto Rican<br>□Columbian<br>□Italian<br>□Turkish<br>□Greek<br>□Non Hispanic/Latino | **Genotype:**<br>☐HgSS<br>☐HgSC<br>☐HgSβ+<br>☐HgSβ○ | **Marital Status:**<br>☐Single<br>☐Married<br>☐Divorced<br>☐Widowed |
| **Primary Dx:** | | **Secondary Dx:** | |
| **Admit Date:** **Time:** | | **Discharge Date:** | |

| Vital Signs: | | | | | |
|---|---|---|---|---|---|
| T: | P: | R: | B/P: | POX: | WT: |
| T: | P: | R: | B/P: | POX: | |
| T: | P: | R: | B/P: | POX: | |
| T: | P: | R: | B/P: | POX: | |
| T: | P: | R: | B/P: | POX: | |
| T: | P: | R: | B/P: | POX: | |

**Oxygen:** □Yes □No **Liters:** **Apparatus:** □ NC □ Mask **Nebs:** □Yes □No

| Frequency of Assessments: | | | |
|---|---|---|---|
| Time: | Pain Intensity: | Prompt Treatment: | Pain Relief: |
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| Frequency of Reassessments: | | | | | |
|---|---|---|---|---|---|
| Timing Q15-30: | Timing after admin of meds: | Pain intensity: | Relief: | Mood: | Sedation level: |
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| **Intravenous Fluids:** | | | | | |
|---|---|---|---|---|---|
| NS 0.9%<br>□Yes □No | Amount: | Rate: | D5%W<br>□Yes □No | Amount: | Rate: |
| NS 0.45%<br>□Yes □No | | | D10%W<br>□Yes □No | | |
| NS 0.225%<br>□Yes □No | | | D5NS<br>□Yes □No | | |
| Ringer's Lactate<br>□Yes □No | | | D5 ½ NS<br>□Yes □No | | |
| D5 Ringer's Lactate<br>□Yes □No | | | D5 1/3 NS<br>□Yes □No | | |
| **Potassium Repletion** □Yes □No | | | **Dosage:** | | |

| **Opioid Administration** | | | | | | |
|---|---|---|---|---|---|---|
| **Adults with ≤ 50K Body Weight:** | | | | | | |
| **Opioid** | **Dosage** | **Frequency** | **IV** | **SQ** | **PCA Basal-Bolus** | |
| Morphine | | | | | | |
| Hydromorphone | | | | | | |
| **Adults with ≥ 50K Body Weight:** | | | | | | |
| **Opioid** | **Dosage** | **Frequency** | **IV** | **SQ** | **PCA Basal-Bolus** | |
| Morphine | | | | | | |
| Hydromorphone | | | | | | |
| Oxymorphone | | | | | | |
| *Meperedine **Not Recommended** | | | | | | |

| **NSAIDS/Adjuvants** | | | | | |
|---|---|---|---|---|---|
| **Medication** | **Dosage** | **Route** | **Frequency** | **Effects** | **Time** |
| Ketorolac | | | | | |
| Motrin | | | | | |
| Naprosyn | | | | | |
| Benadryl | | | | | |
| Atarax | | | | | |
| Zofran | | | | | |
| Muscle Relaxants | | | | | |
| Benzodiazepine | | | | | |
| **Allergies** | | | | | |

| **Location During Admission** | | | | | |
|---|---|---|---|---|---|
| **Oncology 6** | **Med 4** | **ICU** | **Cardiac Stepdown** | **Med 5** | **OB** |
| | | | | | |
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Table 1. *NHLBI SCD Vaso-Occlusive Management Recommendations*

**Table 1**. ***NHLBI SCD Vaso-Occlusive Management Recommendations***

<table>
<tr><td colspan="3">Assessment and Reassessments: for the individual’s pain episode</td></tr>
<tr><td>Initial rapid assessment- of acute painful episode including pain intensity, prompt treatment and relief.</td><td>Reassessments – frequent reassessments every 15-30 minutes after the administration of pain medications for pain intensity, relief, mood, and sedation level.</td><td>Response to therapy – reported reduction in pain intensity of at least 50-60% from the upper end of pain score.</td></tr>
<tr><td colspan="3">Intravenous hydration:</td></tr>
<tr><td>Initial fluid should be 5% dextrose + half-normal saline.</td><td>Add 20 mEq KCl/L adjusted for serum chemistries.</td><td>Total fluids not to exceed 1.5 times maintenance dose.</td></tr>
<tr><td colspan="3">Administration of Oxygen: 2 liters via nasal cannula for patients with pulse oximetry of 92-95%</td></tr>
<tr><td colspan="3">Administration of Opioids and Adjuvants: Short-acting opioid agonists</td></tr>
<tr><td colspan="2">For adults with ≤ 50 kg body weight:<br><br>Morphine: 0.1-0.15 mg/kg every 2-4 hours (parenteral); 0.30 mg/kg every 3-4 hours (oral).<br><br>Hydromorphone: 0.015-0.020 mg/kg every 3-4 hours (parenteral); 0.06-0.08 mg/kg every 3-4 hours (oral).<br><br>*Meperidine: not recommended</td><td>For adults with ≥ 50 kg body weight:<br><br>Morphine: 5-10 mg every 2-4 hours (parenteral);<br>10-30 mg every 3-4 hours (oral).<br><br>Hydromorphone: 1.5 mg every 3-4 hours (parenteral); 7.5 mg every 3-4 hours (oral).<br><br>Oxymorphone: 1.0-1.5 mg every 6hours (parenteral) or 0.5 mg IV and cautiously titrate upward. *Meperidine: not recommended</td></tr>
<tr><td colspan="3">Other routes of administration: Subcutaneous (for the individual with poor or no venous access to prevent delays in treatment) and patient controlled analgesia (PCA).</td></tr>
<tr><td colspan="3">Non-steroidal anti-inflammatory drugs (NSAIDS):<br><br>Ketorolac (parenteral) for inadequate analgesia after optimal titration or when the side effects of opioids are problematic (maximum use of 5 days/month).</td></tr>
</table>

*Note. NHLBI Guidelines 2002*

**Table 2.**

**Demographic Information (n=54)**

| Demographics | n | Percentage |
|---|---|---|
| Gender | | |
| Male | 23 | 42.6% |
| Female | 31 | 57.4% |
| Race | | |
| African American | 48 | 88.9% |
| White | 1 | 1.9% |
| Hispanics | 5 | 9.3% |
| Marital Status | | |
| Single | 45 | 83.3% |
| Married | 5 | 9.3% |
| Divorced | 4 | 7.4% |
| Genotype | | |
| HgSS | 38 | 70.4% |
| HgSC | 10 | 18.5% |
| HgSB+ | 6 | 11.1% |

**Table 3.**

**Pulse Oximetry Measurements (N = 168)**

| Inpatient Oximetry (n=117) | | | Observation Oximetry (n=51) | | |
|---|---|---|---|---|---|
| Measurements | n | % | Measurements | n | % |
| 90 | 0 | 0 | 90 | 1 | 2.0% |
| 92 | 2 | 1.7% | 92 | 1 | 2.0% |
| 93 | 6 | 5.2% | 93 | 1 | 2.0% |
| 94 | 8 | 6.9% | 94 | 3 | 5.9% |
| 95 | 9 | 7.8% | 95 | 2 | 3.9% |
| 96 | 9 | 7.8% | 96 | 4 | 7.8% |
| 97 | 14 | 12.1% | 97 | 6 | 11.8% |
| 98 | 19 | 16.2% | 98 | 9 | 17.6% |
| 99 | 22 | 19.0% | 99 | 15 | 29.4% |
| 100 | 27 | 23.3% | 100 | 9 | 17.6% |
| No documented data | 1 | .9% | | | |

Table 4**.**

**Pain Intensity Scores**

| Inpatient | | | Observation | | |
|---|---|---|---|---|---|
| Pain Intensity Scores | n | Percentage | Pain Intensity Scores | n | Percentage |
| 0 | 1 | 0.9 | 0 | 0 | 0.0 |
| 1 | 0 | 0.0 | 1 | 0 | 0.0 |
| 2 | 0 | 0.0 | 2 | 0 | 0.0 |
| 3 | 1 | 0.9 | 3 | 0 | 0.0 |
| 4 | 5 | 4.3 | 4 | 0 | 0.0 |
| 5 | 9 | 7.8 | 5 | 4 | 8.0 |
| 6 | 20 | 17.2 | 6 | 6 | 12.0 |
| 7 | 17 | 14.7 | 7 | 6 | 12.0 |
| 8 | 26 | 22.3 | 8 | 16 | 32.0 |
| 9 | 17 | 14.7 | 9 | 10 | 20.0 |
| 10 | 20 | 17.2 | 10 | 8 | 16.0 |
| No documented scores | 1 | | | 1 | |

**Table 5.**

**Patient Pain Goals**

| Inpatient (n=56) | | | Observation (n=20) | | |
|---|---|---|---|---|---|
| Patient Desired Pain Goal | | | Patient Desired Pain Goal | | |
| Pain Goal | n | Percentage | Pain Goal | n | Percentage |
| 0 | 15 | 26.8 | 0 | 8 | 40.0 |
| 2 | 2 | 3.6 | 2 | 2 | 10.0 |
| 3 | 15 | 26.8 | 3 | 2 | 10.0 |
| 4 | 11 | 19.6 | 4 | 5 | 25.0 |
| 5 | 3 | 5.4 | 5 | 0 | 0 |
| 6 | 8 | 14.3 | 6 | 2 | 10.0 |
| 7 | 2 | 3.6 | 7 | 1 | 5.0 |

Note. Data was not documented for n = 61 inpatient and 31 observation patient stays.

**Table 6.**

**Intravenous Fluids**

| IVFs (Inpatient) | n | % | IVFs (Observation) | n | % |
|---|---|---|---|---|---|
| D5 NS 0.45% | 46 | 40.0 | D5 NS 0.45% | 21 | 44.7 |
| NS 0.9% | 19 | 16.5 | NS 0.9% | 7 | 14.9 |
| NS 0.45% | 50 | 43.5 | NS 0.45% | 19 | 40.4 |
| No documented data | 2 | | No documented data | 4 | |

**Table 7.**

**Intravenous Fluid Rates**

| Adequate Rate (Inpatient) | n | % | Adequate Rate (Observation) | n | % |
|---|---|---|---|---|---|
| Yes | 46 | 39.3 | Yes | 21 | 41.2 |
| Too low | 69 | 59.0 | Too low | 24 | 47.1 |
| Too much | 0 | 0 | Too much | 2 | 3.9 |
| Not administered | 2 | 1.7 | Not administered | 4 | 7.8 |

**Table 8.**

**Opioid Medications**

| NHLBI Guidelines | (Inpatient) n=117 | % | (Outpatient) n=51 | % |
|---|---|---|---|---|
| Morphine | 17 | 14.5 | 6 | 11.8 |
| Hydromorphone | 99 | 84.6 | 45 | 88.2 |
| None | 1 | 0.9 | 0 | 0 |

**Table 9.**

**Non-Steroidal Anti-inflammatory Drugs**

| NSAIDS | Dosage | Interval | (Inpt) n | % | (Outpt) n | % |
|---|---|---|---|---|---|---|
| Ketorolac | 15mg-30mg | Every 6 hours | 75 | 100 | 24 | 100 |
| Ibuprofen | 400mg-800mg | Every 4-6 hours | 0 | 0 | 0 | 0 |
| Naprosyn | 500mg | Every 12 hours | 0 | 0 | 0 | 0 |

| Route | (Inpatient) n | % | Outpt)n | % |
|---|---|---|---|---|
| IV | 67 | 93.1 | 22 | 95.7 |
| Oral | 5 | 6.9 | 1 | 4.3 |
| No documented data | 45 | | 28 | |

| Doses Administered | (Inpt) n | % | (Outpt) n | % |
|---|---|---|---|---|
| 1 | 21 | 29.2 | 11 | 47.8 |
| 2 | 31 | 43.1 | 6 | 26.1 |
| 3 | 16 | 22.2 | 4 | 17.4 |
| 4 | 4 | 5.5 | 2 | 8.7 |
| No documented data | 45 | | 28 | |

**Table 10.**

**Inpatient Adjuvants**

| Adjuvants | Dosage | Interval | n | percentage | Indication | n | (%) |
|---|---|---|---|---|---|---|---|
| Benadryl | 25mg-50mg | 4-6 hours | 45 | 59.2 | Pruritus | 44 | 57.9 |
| Atarax | 25mg | 4-6 hours | 1 | 1.3 | Pruritus | 1 | 1.3 |
| Zofran | 4mg-8mg | 4-6 hours | 16 | 21.1 | Nausea | 16 | 21.1 |
| Baclofen | 10mg | 8 hours | 2 | 2.6 | Spasms | 2 | 2.6 |
| Lyrica | 50mg-600mg | 12 hours | 4 | 5.3 | Pain | 4 | 5.1 |
| Neurontin | 100mg-900mg | 8-12 hours | 3 | 3.9 | Pain | 3 | 4.1 |
| Ativan | 0.25mg-1mg | 6-12 hours | 5 | 6.6 | Anxiety | 6 | 7.9 |
| No documented data | | | 41 | | | 66 | |

| **Route** | **n** | **Percentage** |
|---|---|---|
| IV | 19 | 24.7 |
| Oral | 58 | 75.3 |
| No documented data | 40 | |

| **Number of Doses Administered** | **n** | **Percentage** |
|---|---|---|
| 1 | 29 | 39.2 |
| 2 | 21 | 28.2 |
| 3 | 9 | 12.2 |
| 4 | 7 | 9.5 |
| 5 | 3 | 4.1 |
| 6 | 4 | 5.4 |
| 7 | 1 | 1.4 |
| No documented doses | 43 | |

**Table 11.**

**Observation Adjuvants**

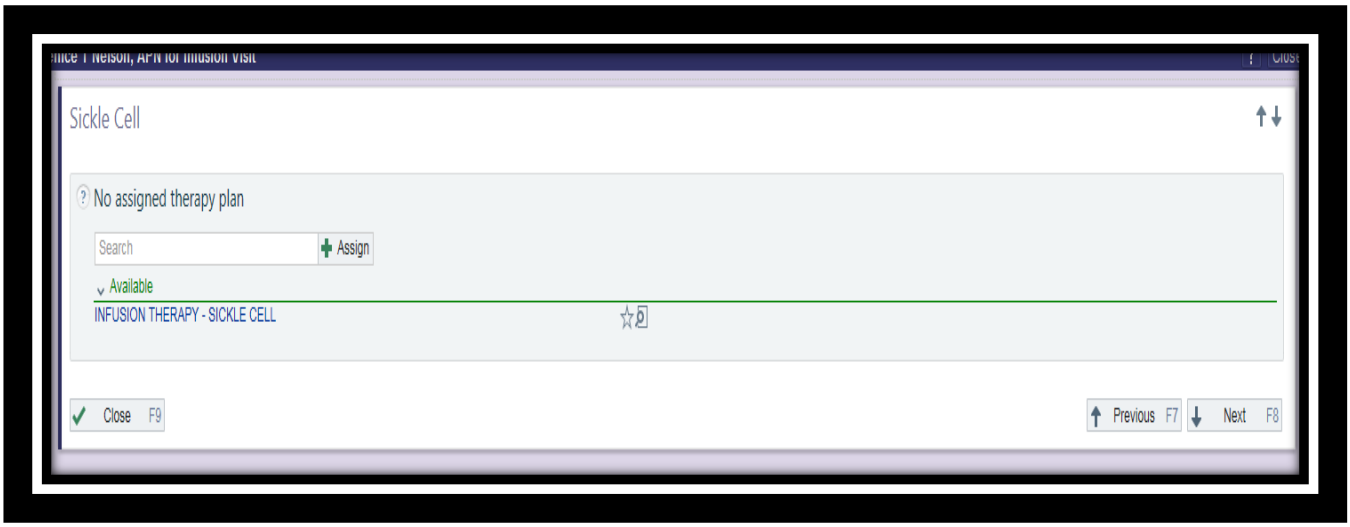
| Adjuvants | Dosage | Interval | n | (%) | Indication | n | (%) |
|---|---|---|---|---|---|---|---|
| Benadryl | 25mg-50mg | 4-6 hours | 17 | 60.7 | Pruritus | 17 | 60.7 |
| Atarax | 25mg | 4-6 hours | 1 | 3.6 | Pruritus | 0 | 0 |
| Zofran | 4mg-8mg | 4-6 hours | 5 | 17.9 | Nausea | 5 | 17.9 |
| Baclofen | 10mg | 8 hours | 0 | 0 | Spasms | 0 | 0 |
| Lyrica | 50mg-600mg | 12 hours | 1 | 3.6 | Pain | 1 | 3.5 |
| Neurontin | 100mg-900mg | 8-12 hours | 1 | 3.6 | Pain | 1 | 3.5 |
| Ativan | 0.25mg-1mg | 6-12 hours | 3 | 10.6 | Anxiety | 4 | 14.4 |
| No documented doses | | | 23 | | | 23 | |

| **Route** | **n** | **Percentage** |
|---|---|---|
| IV | 8 | 28.6 |
| Oral | 20 | 71.4 |
| No documented data | 23 | |

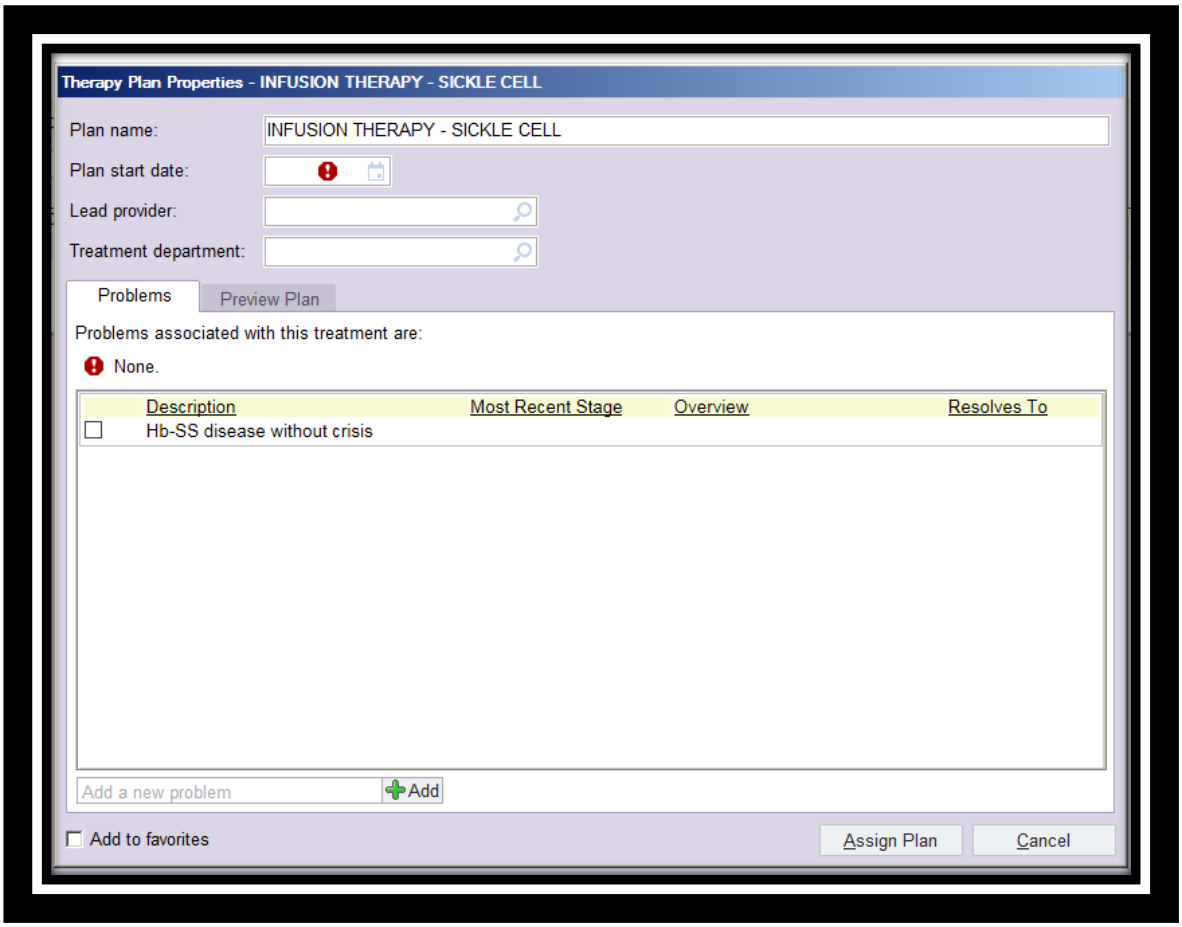
| **Number of Doses Administered** | **n** | **Percentage** |
|---|---|---|
| 1 | 10 | 35.7 |
| 2 | 13 | 46.4 |
| 3 | 3 | 10.7 |
| 4 | 0 | 0 |
| 5 | 1 | 3.6 |
| 6 | 0 | 0 |
| 7 | 1 | 3.6 |
| No documented doses | 43 | |

Clinical Dashboard Exhibits

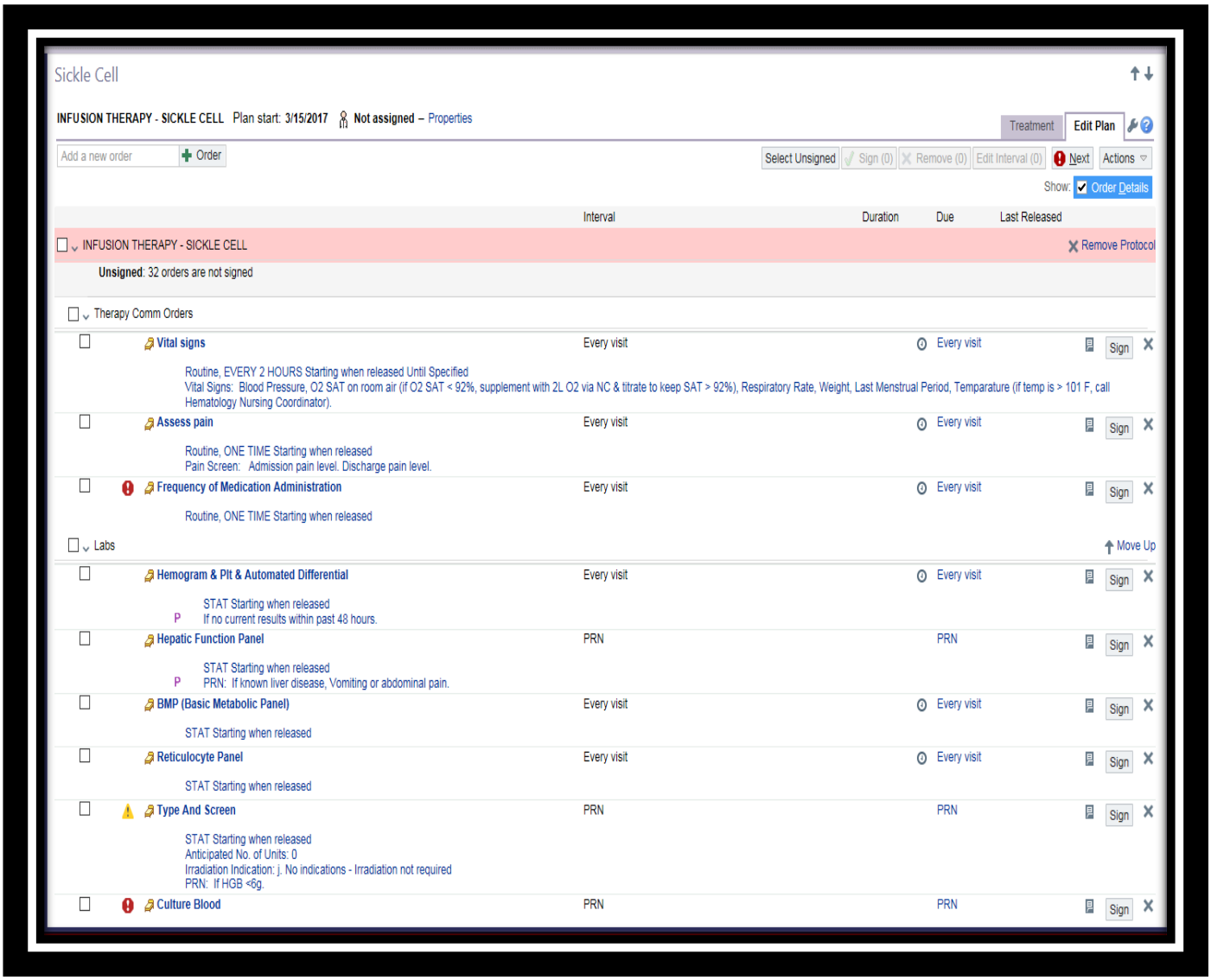
## Exhibit A. Sickle Cell Infusion Order Set Sample



## Exhibit B. SCD Order Entry Set Sample

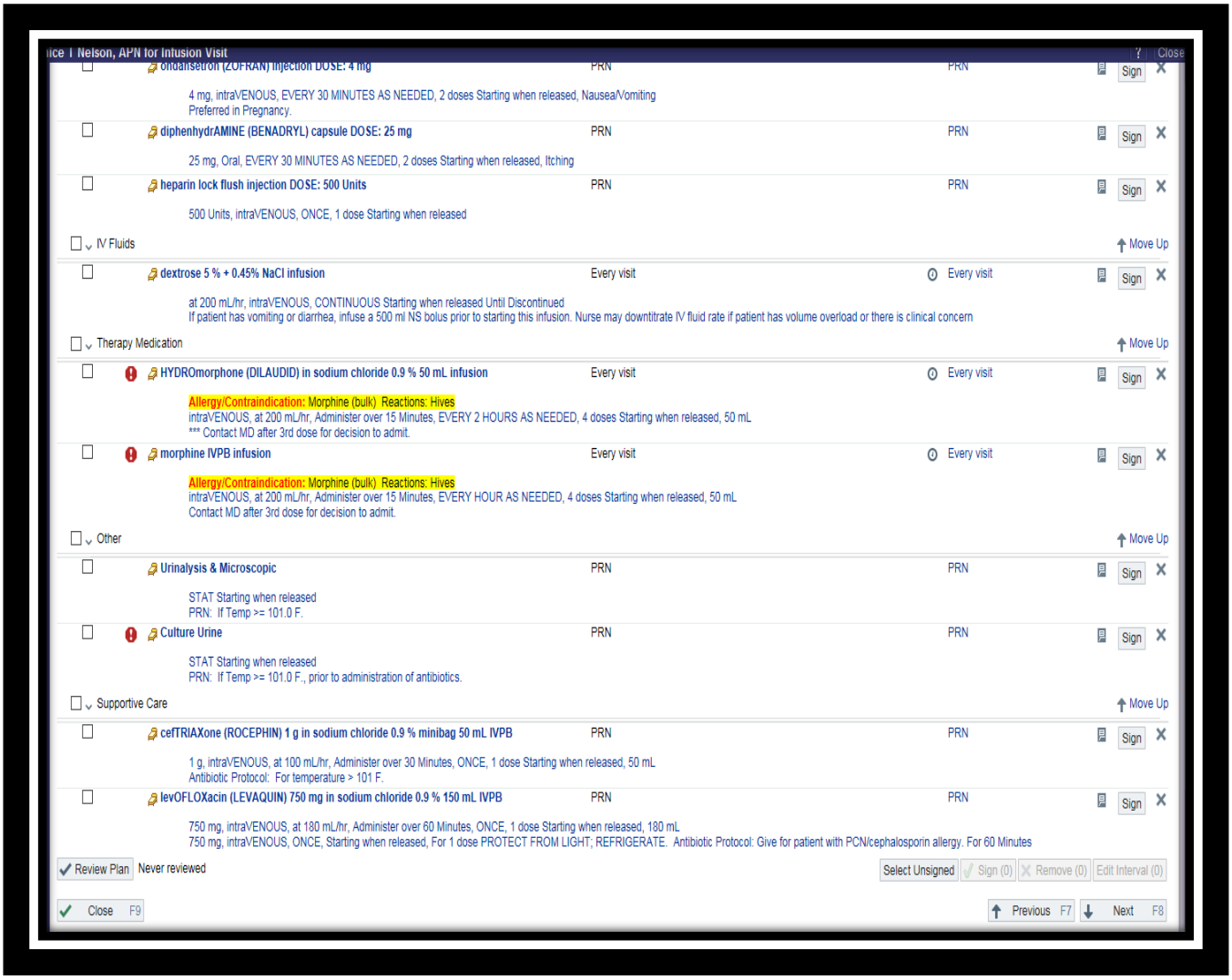


## Exhibit C. SCD Order Set Sample A



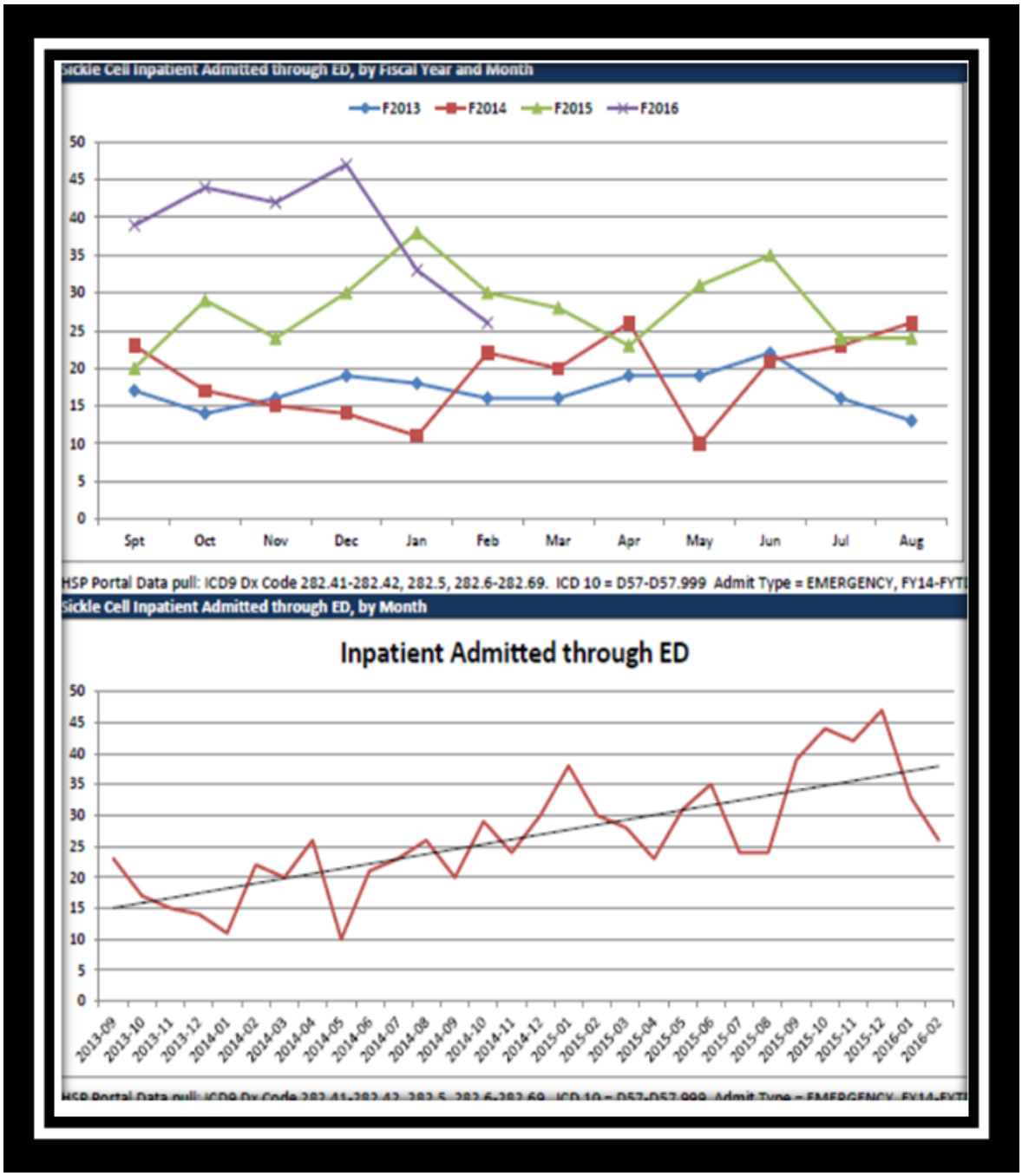
## Exhibit D. SCD Order Set Sample B

## Exhibit. E SCD Order Set Sample C

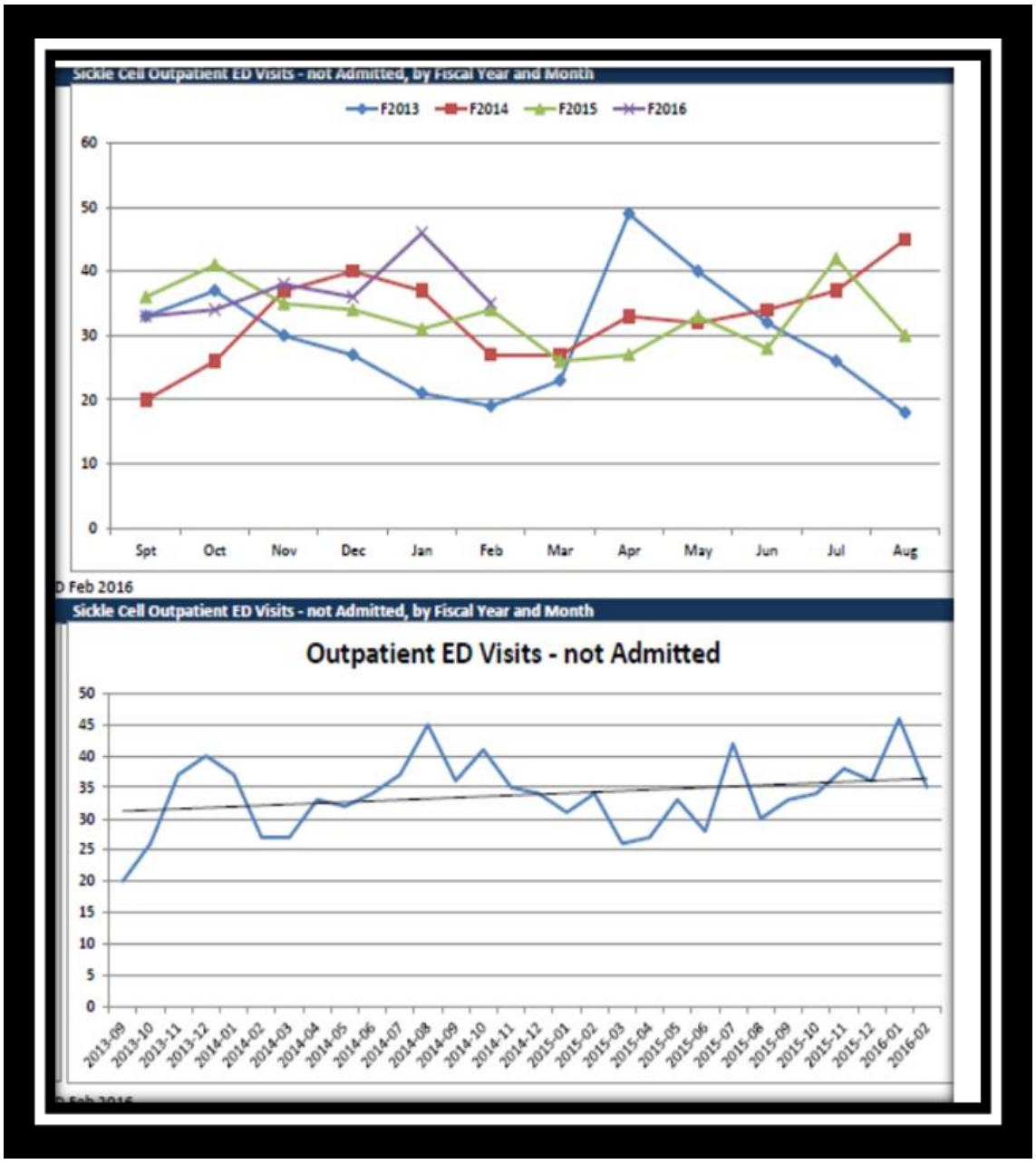


## Exhibit F. Clinical Dashboard Sample

## Exhibit G. Clinical Dashboard Sample A



## Exhibit H. Clinical Dashboard Sample B



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