Development of a Program to Improve the Management of Medicaid Recipients with Sickle Cell Disease in Florida

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I. ICD-9 Algorithms for Identifying the Medicaid Sickle Cell Disease Population

Please see the June 2003 Florida Center for Medicaid and Uninsured report by Lottenberg et al.: Assessing the prevalence of Sickle Cell Disease in Florida Medicaid beneficiaries using data from the Florida Medicaid Files (p 3-6) for the initial report. The relevant data are included for this report.

Estimating the Number of Medicaid Beneficiaries with Sickle Cell Disease

Sickle cell disease is a term that encompasses a group of inherited hemoglobin disorders which include hemoglobin S concentrations that are sufficient to cause sickling and disease manifestations under conditions routinely encountered by affected patients. In Florida, the most common form of the disease is Hemoglobin SS (also identified as sickle cell anemia). Other genotypes falling within the category of sickle cell disease are typically double heterozygote conditions including Hemoglobin SC, Hemoglobin S/β thalassemia, Hemoglobin SD, Hemoglobin SOArab. Sickle cell trait is the "carrier" state with approximately 50% Hemoglobin S and 50% of the normal hemoglobin A which usually confers no major adverse health consequences.

TABLE 1 Relevant ICD-9 codes for evaluating the Florida sickle cell disease Medicaid recipients

Description	ICD-9 code
Sickle cell trait	282.5
Sickle cell anemia	282.6
Sickle cell anemia, unspecified	282.60
Hb- S disease without mention of crisis	282.61
Hb-S with mention of crisis	282.62
Sickle cell/ Hb C disease	282.63
Thalassemias	282.4

We examined data from the Florida Medicaid program for the following fiscal years: 1997-1998; 1998-1999; 1999-2000; 2000-2001. Data from the eligibility files were linked to claims files for inpatient, outpatient, emergency rooms, long-term care and pharmacy claims. A beneficiary was defined as a sickle cell case if that specific individual was eligible for receipt of services at any time during the year 2000, and had had also received a target diagnosis during any of the four fiscal years on any type of claims.

Three different combinations of target ICD-9 codes were employed:

A narrow definition, i.e., 282.62 which is defined as Hb-S disease with mention of crisis;

A mid-range definition expands the narrow definition to include 282.61 which is defined as Hb-S disease without mention of crisis.
A broad definition expands the mid-range definition to include 282.4 which includes Thalassemia-Hb-S disease, but also includes Thalassemias without associated Hb-S.
A very broad definition expands the previous mid-range definition to include 282.60 which is defined as sickle cell anemia, unspecified.
Table 2 displays the estimates based on analysis of this file.

Table 2 Estimates of the number of Medicaid beneficiaries with sickle cell disease, Florida, Calendar Year 2000

Narrow Dx (282.62)	Mid -range Dx (282.62 or 282.61)	Broad Dx (282.62, 282.61 or 282.4)	Very Broad Dx (282.62, 282.61 or 282.60)
2,655	3,268	4,560	6,192

It should be noted that there is a quite sizeable increase in the estimated population when either the Thalassemias (282.4) or the undifferentiated sickle cell disease code (282.60) is included. Another piece of information, available from the claims files, is the presence and number of claims for sickle cell trait, i.e., 282.5. Because it is impossible for an individual to have both trait and disease, and because coding error might occur, we cross tabulated individuals in Table 3 according to the number of trait claims that were generated on these individuals over the 4-year period. It is evident, from the results displayed in Table 2 that depending on the definition used, 10 to 15 percent of beneficiaries are likely to have a contradictory combination of claims. Obviously some of these individuals might be persons thought by their health care provider to have a trait but subsequently tested and found to have disease, or more rarely thought to have disease, but subsequently proven to have trait. However, further analyses of claims revealed that the temporal priority of claims with 282.5 with respect to claims with diagnoses of **282.62 or 282.61 or 282.60** were no more typical than other arrangements, suggesting that inconsistent coding was present in about 5-10 percent of cases. Unfortunately, we have no way of determining whether a specific individual with both trait and disease codes on claims is a false positive or a false negative. Consequently we chose to err on the side of inclusion and focus our attention on definitions that included individuals with the targeted diagnoses, regardless of whether or not they had ever had a 282.5 claim associated with an episode of care.

Table 3 Variations in the estimated number of Medicaid beneficiaries

Cumulative number of trait claims (282.5)	Narrow Dx (282.62)	Mid -range Dx (282.62 or 282.61)	Broad Dx (282.62 or 282.61 or 282.4)	Very Broad Dx (282.62 or 282.61 or 282.60)
None	2,293	2,872	4,133	5,541
0-1	2,472	3,071	4,447	5,890
0-2	2,531	3,137	4,418	6,003
All cases	2,655	3,268	4,560	6,192

Estimating the Population of Florida with Sickle Cell Disease

In this section we attempt to estimate the prevalence of SCD population in the State of Florida. We used 2000 census data and a previously published algorithm to estimate the population with SCD. We chose to assess the prevalence of SCD according to a previously published algorithm (Sprinkle RH, Hynes DM, Konrad TR. Is universal neonatal hemoglobinopathy screening cost-effective? Arch Ped & Adol Med. May, 1994;148:461-469). This information was applied to the State of Florida's year 2000 Census Data (URL:http://www.labormarketinfo.com/census2000/C2SS/c2ss.htm, accessed on March 24, 2002). The results are displayed in Table 3.

This algorithm uses the widely accepted figure of 1:450 for the African American population as a prevalence estimate. In addition, we estimated that individuals of Hispanic ethnicity in Florida might have a somewhat elevated risk of SCD and used the figure of 1:3600. This was based on comparable estimates from Puerto Rico and upon an examination of the composition of population, especially in South Florida where Hispanic populations from Cuba, Puerto Rico, the Dominican Republic, and other Caribbean islands are likely to have more than a nominal presence of persons of African ancestry. It should be noted that our estimates make the same assumptions about any census undercount, as do the official census statistics.

Table 4 Estimates of the population with sickle cell disease in the state of Florida, 2000.

	Florida Population	Rate	Estimated affected persons
Black	**2,471,730**	**1: 450**	**5,493**
Hispanic	**2,682,715**	**1: 3600**	**745**
Overall			**6,238**

By using the Medicaid generated estimates as a numerator and estimates based on the 2000 census data as a denominator, we can conclude that the Medicaid program has a significant, probably a majority, penetration of the Sickle Cell population in the State of Florida. We can also make some deductions about how realistic our various definitions of affected Medicaid beneficiaries are, because the number of affected Medicaid beneficiaries cannot exceed the total population. Thus, for example, both the broad and very broad definitions are likely to incorporate information from some false positives, it is likely that at a minimum, 40 percent of Floridians with Sickle Cell disease are enrolled in the Medicaid program. The upper limit is likely to be in the range of 60-70 percent. Our mid-range estimate of 52.4 percent, which estimates that 3,268 Medicaid beneficiaries have SCD, appears to be the most reasonable one and will serve as the basis for our further studies which break down utilization of services and pharmaceuticals by demographic and geographic factors.

Table 5 Estimates of the percentage of the sickle cell disease population covered by the Florida Medicaid Program, 2000

SCD Patients (est)	Narrow (282.62)	Mid-range (282.62 & 282.61)	Broad Dx (282.62, 282.61 or 282.4)	Very Broad Dx (282.62, 282.61 or 282.60)
6,238	2,655	3.268	4.560	6,192
	42.6%	52.4%	73.1%	99.3%

The ICD-9 selection algorithm used for this study was the mid-range definition of SCD (282.61/282.62). Visual inspection of the top 300 of patient files rank ordered according to resource utilization costs revealed there were recipients included in the cohort with the diagnosis of hemophilia (ICD-9 code: 286.0). It is inferred these are included by miscoding and these recipients were removed from the files included for the analysis.

Table 6

Florida Medicaid Recipients with Sickle Cell Disease (2001)

Characteristic of recipients	Number (%)
Age (years)	
0- 15	2038 (57.5)
16-25	744 (21.0)
26-35	365 (10.3)
>35	400 (11.3)
Sex	
Female	1873 (52.8)

Figure 1

Florida Contains 11 Community Health Purchasing Alliance Regions

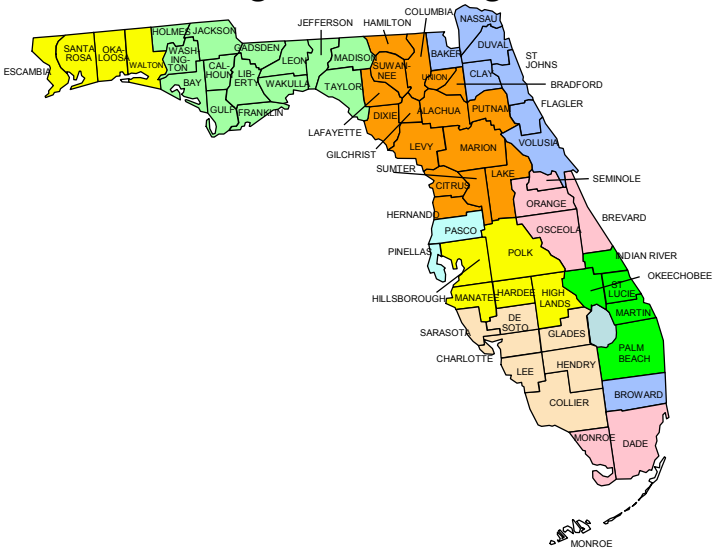

Table 7

Medicaid Charges by Age of Beneficiaries (2001)

Age Group	Number	Mean Charges ($)	Aggregate Charges to Medicaid ($)	Per Capita Cost Ratio	Percent of Charges to Medicaid
All 16+	1509	12,421	18,743,279	1.000	100
16 - 20	427	14,997	6,403,719	1.207	34
21 -25	317	12,254	3,884,518	0.987	21
26- 30	213	11,055	2,354,715	0.890	13
31- 35	152	13,305	2,022,360	1.071	11
36- 40	159	10,597	1,684,923	0.853	9
41- 45	106	9,859	1,045,054	0.794	6
46- 50	66	10,371	684,486	0.835	4
50+	69	9,616	663,504	0.774	4

II. Survey of Hydroxyurea Therapy for Sickle Cell Disease in Community-Based and Academic Clinical Practices

Purpose: The efficacy of hydroxyurea (HU) in treatment of adults with sickle cell disease (SCD) has been demonstrated in a major multicenter clinical trial and its benefit has been further supported by reports from medical centers with interest in SCD. However, there remains concern that HU is underutilized in the management of symptomatic SCD. The objective of this study is to develop a clinical practice tool for the use of HU by community-based physicians. Prior to the development of this tool, a survey was sent to practicing community and university affiliated/based hematologist/oncologists to gain insight into the patterns of HU use in the treatment of SCD.

Methods: A 27-item 4-page questionnaire was developed and mailed to Florida and North Carolina hematologists/oncologists (H/Os). The goal of this questionnaire was to collect data about physicians' professional background, characteristics of the SCD patient population as well as indications for prescribing HU and management strategies used for patients on HU. Data analysis consisted of comparing responses from community–based H/Os to a subset of H/Os practicing at university based or university-affiliated hospitals and caring for a minimum of 3 SCD patients per month (academic H/Os). The results were then used to develop a clinical practice tool that can be used to evaluate if patients are candidates for HU and to guide the management of patients on HU therapy.

Table 8 Professional background and sickle cell disease related practice patterns of community hematologists/oncologists

Characteristic	Percent
Professional background	
Finished medical school before 1975	28
Finished medical school in 1985 or later	29
Finished fellowship before 1985	44
Finished fellowship in 1995 or later	16
Not fellowship trained	0
Currently practice hematology and oncology	94
Board certified in hematology and oncology	46
Attend Am. Soc. of Hematology meetings	59
Attend other hematology seminars	59
Practice in Florida	78
Practice in North Carolina	22
Sickle Cell Practice Patterns	
See fewer than one SCD patient per month	43
See 6 or more SCD patients per month	8
Has fewer than one SCD pt/mo in hospital	57
Cares for own hospitalized SCD patients	54
Uses medicine service for SCD patients	48
Uses hem/onc service for SCD patients	21
Uses HU for 10% or more of SCD pts	55
Uses NIH guidelines to manage SCD patients	35

Table 9 Sickle cell disease patients treated with hydroxyurea by community hematologists/oncologists

Percent of SCD patients treated with hydroxyurea	Number*	Percent
under 10%	75	45
10-30%	32	20
31-60%	33	20
61-90%	18	11
over 90%	8	5
Total	166	100.0

*18 physicians did not answer this question

Table 10 Indications for hydroxyurea use by community hematologists/oncologists stratified by frequency of hydroxyurea use

Indications	Percent of H/Os (N=156)
>3 painful crises/year	76%
narcotic use for pain	58%
acute chest syndrome	43%
stroke history	40%
symptomatic severe anemia	31%
priapism	27%
low hemoglobin F levels	29%
ankle ulcers	19%
renal failure	7%
pulmonary hypertension	7%
other criterion	5%
elevated white cell count	3%

Table 11 Importance of various criteria for <u>not</u> prescribing hydroxyurea when it might otherwise be indicated (community hematologists/oncologists)

Reason for not prescribing HU	Percent rating "*Not Important*"	Percent rating "*Important*"	Percent rating "*Very Important*"
Compliance	9	28	62
Contraception, pregnancy issues	20	39	40
Patients' anticipation of side effects	28	56	16
Patient's age	49	36	14
Cost	41	45	14
Concern about carcinogenic potential	60	29	11
Doubt effectiveness	59	36	4

Results: There were 184 community H/O respondents and 30 academic H/O who met the criteria of seeing at least 3 SCD patients/month. Most community H/Os reported seeing relatively few SCD patients in their practices; 74% saw less than 2 per month and 57% had less than 1 SCD patient hospitalized/month. Relatively few community H/Os referred patients to a specialized consultation center prior to initiating HU therapy. Our survey listed 11 potential criteria for placing patients on HU. Most frequently, invoked criteria by community H/Os were greater than 3 painful crises per year (76%), chronic pain requiring frequent narcotics (58%) and acute chest syndrome (43%). These were also the top 3 criteria used by academic H/Os who more often prescribed HU for acute chest syndrome (70% vs. 43%, p =. 006). Of the remaining indications, severe anemia was also cited more often by academic H/Os (60% vs 40%, p =. 04) as a reason for prescribing HU. Criteria for increasing HU dosing were similar for both groups. There was no difference in the monitoring of routine laboratory tests, however academic H/Os more frequently followed red cell MCV values (90% vs. 36%, p =. 001) and hemoglobin F levels (90% vs.77%, p =. 005). Concerns expressed by both groups for not prescribing HU when otherwise indicated included compliance issues, lack of appropriate contraception, doubts about effectiveness, and patient's concern of potential side effects. Only 35% of the community H/Os indicated that they used NIH published guidelines in the management of their SCD patients. Based on the results of this survey, we have developed a hydroxyurea clinical practice tool to help increase consideration of HU use in patients with appropriate clinical indications. In addition information addressing benefits, potential risks, dosing recommendations, guidelines for monitoring therapy, and strategies to measure compliance will be included.

III. Improving the Use of Hydroxyurea: Development of A Clinical Assessment Tool and Implementation of a Clinical Trial to Determine Physician Acceptability

Methods

An extensive literature review on the use of hydroxyurea in the treatment of patients with sickle cell disease was carried out. All clinical trials and summations of the results as provided by the Cochrane Review (insert title) were evaluated. The National Library of Medicine PubPed literature search using "hydroxyurea" and "sickle cell disease" as the key words was used to identify all relevant literature. The clinical assessment tool was developed with the following subject areas: 1) criteria for identifying patients that are potential candidates for receiving hydroxyurea therapy, 2) provisions for the physician with relevant information for the sickle cell patient and his/her family, 3) guidelines on how to initiate therapy and the necessary baseline laboratory evaluations, 4) guidelines on how to monitor therapy and escalate the dose, 5) information on how to address lack of clinical response. The initial draft of the tool was developed by input from local academic hematologists, sickle cell disease nurse specialists, and pharmacists. In addition, selected community hematologists/oncologists and hematology/oncology fellow trainees were asked to provide input. The document was modified according to these recommendations and the clinical assessment tool was then sent out for formal review by experts in sickle cell disease hydroxyurea (including physicians directly involved in the major multicenter clinical trial of hydroxyurea [University of Florida Institutional Review Board] approval was obtained prior to this mailing). The clinical assessment tool was refined based on these key recommendations provided by these individuals. The clinical

practice assessment tool, patient encounter forms, and a patient log were reviewed by the University of Florida IRB and approved for use in a community physician trial to determine the acceptability of the instrument. Clinical sites throughout the state of Florida have been identified and clinical assessment tools and other resources have been sent out to 6 group practices. The period of testing will be from June 15 – September 30, 2004. The utility of the instrument in managing sickle cell patients and optimizing hydroxyurea therapy will be assessed by tabulating results from the patient encounter form, an end of the project questionnaire and phone interviews of the physicians participating in the clinical trial.

See appendix A for the following:

Sickle Cell Patient Encounter Form

Introduction to the Hydroxyurea Clinical Practice Tool

Cover Letter for Hydroxyurea Survey

Hydroxyurea Clinical Practice Tool

Patient Log for UF Sickle Cell Disease Hydroxyurea Project

IV. Development of a Patient Educational Video to Enhance the Use of Hydroxyurea

Background

Hydroxyurea is a chemotherapy drug that has been proven by clinical trials to reduce the amount of pain crisis, hospitalizations, and episodes of acute chest syndrome in sickle cell patients that respond to it. It was FDA-approved in 1998 and is the only drug at this time that can change the natural history of sickle cell disease. There are associated risks, so patients need to be adequately informed to weigh the benefits and adverse effects.

Starting a chemotherapy drug is not a decision to be taken lightly. The choice is one that may need to be thought over at home, or discussed with family members. Patients may receive pamphlets to learn more about the drug at home. Yet, according to results of the 1993 National Adult Literacy Survey, only half of adult Americans have literacy skills that are at most limited. Written education materials will not inform this large population. A patient education video may be an effective way to communicate the possible benefits of hydroxyurea. Patient education videos have been an effective format for educating patients, although the practice is relatively new. It is uncertain whether patient education videos will be an efficient method of communicating issues surrounding hydroxyurea therapy with the sickle cell disease patient population.

Problems in Literacy

Poor functional health literacy is common among patients who have low educational attainment, and among older patients and racial and ethnic minorities. Health literacy is defined as a measure of a patient's ability to perform basic reading and numerical tasks required to function in the health care environment. Poor adherence and high hospitalization rates among people with low literacy add $30 to 73 billion to the annual health care bill. Poor functional health literacy is independently associated with poor self-rated health, poor understanding of one’s medical condition and its management, and higher utilization of

healthcare services. Although the reasons for poor health literacy are not clear, it is likely that ineffective communication in the health care environment plays a role.

A person who is illiterate is probably not an informed health care consumer. If the patient is frightened, embarrassed, or not savvy enough to ask the right questions, the patient is apt to ignore their treatment plan. This could have severe consequences.

Patient Education Videos

Educational videos may be a superior form of intervention for the delivery of information to patients in general, especially those with poor literacy skills. Videos provide multiple messages through non-verbal and representational communication. Educational videos are also time efficient in the outpatient setting, are easily incorporated into busy health care settings, and can be taken home by the patient for repeat viewings. This is important, especially when dealing with a predominantly African American population who makes many health decisions with the help of family members. Patient education videos allow for family members to receive accurate first hand information so they can help patients make informed decisions. These important choices will influence an individual's health behavior, utilization of health services, and physical and psychological well-being.

Patient education videos have been successful in encouraging women to screen themselves for cancer. Although most of the study participants had been taught how to engage in self breast-examinations previously, the information had not been retained sufficiently. Knowledge about the importance of screening and breast cancer risks clearly improved with the use of patient videos. The video's impact on long term knowledge and skills are not known, but the short-term gains are apparent.

Research studies conducted on women's breast examination behaviors proved that the African American community is influenced more by testimonials from people who are similar to themselves. Seeing a model similar to oneself accomplishing difficult tasks is more convincing than observing those who are different achieve success. African American women who watched videos of same-race female models practicing breast examinations were more likely to believe that practice was effective than those who watched videos with different-race models. The African American women perceived advice from African American physicians as more credible than those of other races. The study's results indicate that using age and race sensitive video programs positively influence outcomes, both in terms of knowledge gains and increased breast self examination ability.

A review of patient educational material on sickle cell disease and hydroxyurea therapy was conducted, including pamphlets, videos and websites. Individuals with expertise in health and science communication, as well as video production, worked with academic hematologists to address the subject matter and presentation format of the video. In addition, patient educational material pertaining to medical conditions other than sickle cell disease was investigated. Formative interviews were performed with key individuals involved in providing health care services to patients with sickle cell disease. Through the perspectives of both the patient and health care providers the goal of this video is to provide the SCD patient with enough information to enable further effective discussion with the prescribing physician concerning the benefits and risks of HU therapy. Three patients with SCD who were currently receiving HU were chosen to give their testimonials for the video. A physician opinion expert with extensive experience in the care of sickle cell disease patients as well as involvement in clinical trials with hydroxyurea was chosen to discuss how the medication works in sickle cell disease and to provide an overview of benefits and risks. In addition, another physician who is a strong sickle cell disease advocate and involved in a large urban sickle cell program, was chosen to address how patients can talk to physicians about issues surrounding treatment with hydroxyurea. These interviews are planned to take place within the next two months.

The camera interviews will be reviewed and a rough script will be created through the use of editing. The initial video product will be reviewed by the project director and other physicians with expertise in sickle cell disease to assure content validity. Subsequently, several patient focus groups will be carried out to judge the effectiveness of the video. The focus group will provide group discussions that will offer direct evidence about similarities and differences in the participants' opinions and experiences. Refinement of the video will be carried out based on the information gained from the focus groups. After further editing approximately 500 copies of the patient educational video will be produced. They will be distributed through physicians' offices as well as by the Sickle Cell Disease Association of Florida community outreach coordinators in three selected regions of Florida. Followup data will be obtained by telephone interviews of physicians and surveys of patients to determine the effect on the patients' understanding of hydroxyurea therapy and the potential impact on treatment decisions.

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V. Recommendations for a Florida Disease Management Initiative for Patients with Sickle Cell Disease

1. Clinical Guidelines/Pathway for Hospital-Based Management of Sickle Cell Painful Episode

Moderate to severe sickle cell painful episodes are treated in the hospital setting using opioid analgesics. The painful episode represents the most common reason for hospital admission and often is a prodrome for more serious consequences such as acute chest syndrome or multi-organ failure. Hospitals with sizable sickle cell disease populations typically will use clinical pathways/guidelines for treatment of the condition, and literature is available to incorporate evidence-based approaches to patient management (see references). These pathways can easily be adapted to smaller hospitals, as pain management represents a priority for the medical inpatient services and sickle cell disease-specific interventions are readily available. In this report we provide the results of a collaborative effort of the University of Florida College of Medicine and Shands Hospital-UF in Gainesville in the development and implementation of a clinical pathway with standardized physician order forms for adult sickle cell disease patients.

The participating groups involved in this project included the Shands Hospital Pain Committee, nursing services of the Medicine units, hospital pharmacy, and physicians participating in the care of adult sickle cell disease patients.

The following reference sources were used to develop the materials:

1) Guideline for the Management of Acute and Chronic Pain in Sickle Cell Disease. APS Clinical Practice Guidelines Series #1 Glenview, IL. American Pain Society.
2) The Management of Sickle Cell Disease, Fourth Edition, NIH Publication No. 95-2117,2002.
3) Guidelines for Standard of Care of Acute Painful Episodes in Patients with Sickle Cell Disease. Developed by Samir K. Ballas, MD, Timothy M. Carlos, MD, Carlton Dampier, MD and the Guidelines Committee, Commonwealth of Pennsylvania, Department of Health.

4) Pain Episode, Sickle Cell Information Center Guidelines. The Georgia Comprehensive Sickle Cell Center at Grady Health System. The Sickle Cell Foundation of Georgia, Inc. Emory University School of Medicine Department of Pediatrics, Atlanta, Georgia.
5) Sickle Cell Disease in Children and Adolescents: Diagnosis, Guidelines for the Comprehensive Care, and Protocols for Management of Acute and Chronic Complications. Mountain States Regional Genetic Services Network, November, 1999.

There are several components to the SCD orders and guidelines:

The physician uses the Inpatient Admission Orders when the SCD patient is admitted to the inpatient unit.

The Clinical Pathway is for nursing services to use to track daily progress of the SCD patient during their hospital stay.

The inpatient Weaning/Transition Protocol is used by the physician and nursing staff to insure an orderly switch from IV to oral pain medications in preparation for discharge and outpatient follow-up in clinic.

Members of the participating groups met on a regular basis to review and modify the orders and guidelines. Individual members of the group took draft versions of the orders and guidelines to colleagues in their specialty areas to get feedback. Once a consensus was reached on the final version of the orders and guidelines it was sent to the hospital forms committee for review and approval.

Prior to placing the hospital approved orders and guidelines on designated inpatient units, a series of inservices were conducted with nursing and administrative support staff. Also, the medical director of the adult SCD program briefed physicians on the use of the orders and guidelines at one of their patient care meetings.

After the orders had been in use for ninety days, the adult SCD nurse specialist requested and received written feedback from the physicians and nurses on ways to improve the orders and guidelines. The orders and guidelines were modified and sent back to the hospital forms committee for approval.

See appendix B for the current version of the orders and guidelines.

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The **Clinical Pathway** is for nursing services to use to track daily progress of the SCD patient during their hospital stay.

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2. Health Care Transition from Pediatric to Adult-Oriented Health Care

The state of Florida has made great strides in providing adequate care for infants and children with sickle cell disease. The well established newborn screening program identifies at risk infants and provides a mechanism to assure timely referral to an established

hematology/oncology center with expertise in sickle cell disease. These centers take advantage of the impressive results of evidence-based therapeutic intervention. Key features of the management program include the early institution of prophylactic penicillin therapy and the use of the recently approved conjugate pneumococcal vaccine. These interventions prevent the life-threatening invasive pneumococcal infection, which accounted for substantial infant mortality. Additional advances include the use of transcranial Doppler studies to identify children at risk for their first stroke and the use of prophylactic red blood cells transfusions for those infants. In addition, chronic transfusion of red blood cells has proved affective as secondary stroke prevention. There have also been recent clinical trials demonstrating that hydroxyurea therapy is effective for pediatric patients. These approaches and others utilized in the comprehensive care of children with sickle cell disease have substantially improved survival. A June 2004 publication from a major sickle cell center reveals that over 85% of children with sickle cell disease receiving care in such a program survive to age 18.

The improved survival for patients with complications of sickle cell disease portends increasingly complex medical problems with co-morbidities. The challenges facing these patients are compounded by the lack of equivalent hematology centers for sickle cell patients that age out of pediatric care. National Institute of Health sponsored sickle cell programs support state of the art care for adults as well as children. However, there are only ten such funded centers in the United States and none of which are in Florida. In the experience of the project director and in discussions with community based hematologists/oncologists throughout Florida, these practice settings are often not well suited for the optimal management of adult sickle cell disease patients. Furthermore, adult patients do not have the ancillary professional support (nursing, psychological, and social) that are available through the pediatric programs.

Our analysis of the Medicaid sickle cell disease recipient data feels that the adolescent and young adult population accounts for substantial costs of resource utilization (see **Section I, Table 7**). The project director in collaboration with Dr. John Reiss and Mr. Robert Gibson of the University of Florida Institute for Child Health Policy have evaluated the opportunity for a health care transition program focused on patients with sickle cell disease. Interventions would follow a needs assessment and transition training in care coordination would address specific problems. Components of the program would include: 1) consultative services from selected experts in sickle cell disease to utilize telemedicine for internet based approaches, 2) healthcare provider web-based training and resources based on available clinical guidelines, 3) procure transition training for young adults with sickle cell disease and their family members, 4) health care coordination potentially provided through the Sickle Cell Disease Association of Florida outreach coordinator network.

3. **Optimizing the Use of Hydroxyurea Therapy for Symptomatic Patients –** Please see Sections **III and IV**

4. **Facilitation of Case Management through Consultation with Sickle Cell Disease Experts**

As sickle cell disease patients age out of pediatric care, there is fragmentation in their medical management. Florida does not have a formal program to address the needs of older adolescents and adult patients with sickle cell disease. Our analyses through discussions with hematologists/oncologists, primary care physicians, representatives of the Florida Sickle Cell

Disease Association, and patients reveal that there are an inadequate number of adult-oriented practitioners with expertise in the management of the complexities of sickle cell disease available. A health care delivery model that would potentially address this problem would be a network of primary care physicians (i.e. internists and family physicians) that have readily available consultative services from sickle cell disease experts and clinical guidelines (e.g. web-based and teleconference resources [see 2002 and 2004 Florida Center for Medicaid and the Uninsured reports by R. Lottenberg]) to provide ongoing preventive health care measures and emergent health care.

The following clinical vignettes are examples of patients referred to an academic hematologist with special interests in sickle cell disease (the project director) and provide insights into the opportunities for assisting community-based physicians in improving health care.

Case 1: A 44-year-old African American woman with Hb SS referred for assistance in management of frequent pain episodes related to her sickle cell disease. The patient's history and assessment showed a pattern of multiple blood transfusions and frequent use of meperidine (Demerol) for pain control. The patient was informed about the benefits and risks of hydroxyurea therapy. It was recommended that the patient start hydroxyurea and recommendations for appropriate dosing and monitoring were provided to the physician. It was recommended to avoid the use of blood transfusions for pain control or asymptomatic anemia. It was also recommended that the patient be placed on a long acting opioid medication (slow release morphine) rather than using meperidine.

Case 2: A 22-year-old African American woman with Hb SS was referred for assistance in management of complications of iron overload related to multiple blood transfusions prescribed for the history of stroke from her sickle cell disease. A detailed discussion took place with the patient and her mother about the patient's cardiac disease secondary to the iron overload related to the large number of previous blood transfusions. The discussion also included weighing the added risk to continuing transfusions vs. giving consideration to discontinuing the administration of red blood cells and using hydroxyurea therapy for secondary stroke prophylaxis. It was also recommended to continue using iron chelation therapy and to begin a phlebotomy program if the patient's hemoglobin level would permit. A lengthy discussion with the referring physician took place and the consultant is continuing to be involved in patient management (communication by telephone and letters).

Case 3: A 21-year-old African American woman with Hb SS and second trimester pregnancy is referred for evaluation and treatment recommendations. She had been admitted to a local hospital on several occasions where she had been treated for pneumonia and sickle cell disease pain episodes. During these admissions the patient had received numerous blood transfusions. The patient was educated and instructed on proper hydration, use of pain medications that are safe in pregnancy and the need to adhere to scheduled appointments. The patient and her physicians are informed of the clinical evidence supporting the recommendation to avoid prophylactic red cell transfusion in pregnancy without complications. An ongoing involvement of the high-risk obstetrics group is assured.

Case 4: A 31-year-old Hispanic male with Hb SS disease is referred for assistance with pain management and evaluation for possible hip surgery. The patient had documented avascular necrosis of the right hip due to his sickle cell disease. The patient was informed about the options of conservative management of the hip problem vs. surgery. The patient's primary care physician received information on optimizing outpatient pain management and giving consideration to a phlebotomy program due to the elevated hemoglobin level. Arrangements for collaboration between the consultant and the orthopedic surgeon were put in place so that if surgery is contemplated appropriate pre- and peri-operative care can be delivered.

Case 5: A 30-year-old African American woman with hemoglobin SS referred for assistance with treatment of her SCD and specifically the use of hydroxyurea. The patient had a history of multiple hospital admissions, approximately once a month over the last five years for painful episodes and several acute chest syndromes. The patient was educated and instructed on proper hydration, pain medication and the use of hydroxyurea. The importance of compliance, attaining the maximum tolerated dose, and the results of the definitive multi-center clinical trial supporting its benefit were reviewed in detail. The patient acknowledged a better understanding of hydroxyurea therapy and a willingness to adhere to the recommended treatment program.

Appendix A

Sickle Cell Patient Encounter Form

We are providing the clinical assessment tool to a select panel of physicians who are caring for sickle cell patients throughout the state of Florida. Our intent is to examine carefully whether and how this clinical assessment tool is used by a busy practitioner like you. We hope that the information provided will be useful to you and your patients.

We would like you to answer these brief questions about **each** SCD patient in your practice encountered during the pilot project time period. Please circle your response.

	Hydroxyurea Clinical Practice Tool	YES	NO	Does not apply in this case
	Did you use the assessment tool with this patient?	YES	NO	
	I used the tool to help me decide about starting HU therapy with a patient	YES	NO	DNA
	I used the tool to monitor a patient who was already on HU therapy	YES	NO	DNA
	I used the tool to terminate HU therapy	YES	NO	DNA
	The tool helped me decide whether or not my patient fit criteria for HU therapy	YES	NO	DNA
	The tool helped me discuss HU risks and benefits with my patient	YES	NO	DNA
	Did you initiate HU therapy with this patient?	YES	NO	
	The tool helped me explain to my patient what to expect with HU therapy	YES	NO	DNA
	The tool helped me explain to my patient about side effects of HU therapy	YES	NO	DNA
	***IF this patient was already on HU was the tool used for dose adjustment*?**	YES	NO	
	Information about the laboratory parameters for dose adjustment was clear	YES	NO	DNA
	The tool was helpful in assessing whether or not the dose was effective	YES	NO	DNA
	Information about the laboratory tests, frequency of testing, and critical values was helpful to me in making the decision to <u>change</u> the monitoring of HU therapy	YES	NO	DNA
	IF patient was already on HU was the tool used to monitor therapy or compliance?	YES	NO	
	I used the tool to assess patient compliance with my prescribed dosage	YES	NO	DNA
	I used the tool to help measure the effectiveness of HU therapy	YES	NO	DNA

Introduction to the Hydroxyurea Clinical Practice Tool

Hydroxyurea is effective in the treatment of sickle cell disease (see literature references). Hydroxyurea therapy may be underused in the management of symptomatic patients. Our earlier research suggested that community-based hematologists/oncologists in Florida would like more information on how to use hydroxyurea more effectively and appropriately. This clinical practice tool was developed in response to that perceived need. We hope you find it useful.

Core Reference Material (summaries available upon request)

The Management of Sickle Cell Disease **(fourth edition); NIH Publication No. 02-2117 July 2002: 162-5. (www.nhlbi.nih.gov/health/prof/blood/sickle/sc_mngt.pdf)**

Effect of hydroxyurea on the frequency of painful crises in sickle cell anemia. Investigators of the Multicenter Study of Hydroxyurea in Sickle Cell Anemia.
Charache S, Terrin ML, Moore RD, et al. N Engl J Med 1995, 332:1317-22.

Effect of hydroxyurea on mortality and morbidity in adult sickle cell anemia: risks and benefits up to 9 years of treatment. Steinberg MH, Barton F, Castro O, et al.
JAMA 2003, 289:1645-51.

The role of hydroxyurea in sickle cell disease. Halsey, C and Roberts, IAG.
British Journal of Hematology 2003, 120:177-186.

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1600 S.W. Archer Road
PO Box 100277
Gainesville, FL 32610-0277
(352) 392-3000
Fax (352) 392-8530

June 11, 2004

Dr. XXXX
Address
Address
Address

Dear Dr. XXXX:

Thank you for agreeing to participate in our project assessing the utility of a hydroxyurea clinical practice tool. We are providing the clinical assessment tool to a select panel of physicians who are caring for sickle cell patients throughout the state of Florida. Our intent is to examine carefully whether and how this clinical assessment tool is used by a busy practitioner like you. We hope that the information provided will be useful to you and your patients. This is part of a research study funded by the state of Florida. We would like to complete the collection of data by September 30, 2004.

Enclosed are **Notebook A** with the **Hydroxyurea Clinical Practice Tool** and **Patient Encounter Forms. Notebook B** contains the **Sickle Cell Disease Patient Log**. PLEASE NOTE THAT THE LIST OF PATIENT NAMES IS TO BE USED BY YOUR CLINICAL PRACTICE ONLY AND NOT PROVIDED TO ME OR THE RESEARCH TEAM. The purpose of this log is to assure that each sickle cell patient in your practice has been considered for evaluation with the clinical practice tool. We will collect the Patient Encounter Forms from you at the end of the study. If you have any questions or comments concerning the clinical practice tool or data entry on the forms please do not hesitate to contact me at 352-392-2976 or by e-mail at: lottenr@medicine.ufl.edu I cannot provide compensation for your efforts, but will provide you the results of this pilot study. I thank you in advance for your contribution.

Sincerely yours,

Richard Lottenberg, MD
Professor of Medicine
Division of Hem/Onc
University of Florida
College of Medicine

Hydroxyurea Clinical Practice Tool

Richard Lottenberg, MD
University of Florida Adult Sickle Cell Disease Program

I. Is the patient a candidate for hydroxyurea therapy?

For patients not enrolled in a chronic transfusion program: age 16 or older, with sickle cell disease (Hemoglobin SS, S/beta^0 thalassemia, S/beta$^+$ thalassemia, or SC)

1. Has the patient been admitted to the hospital ≥ 3 times in a 12-month period of time for the treatment of sickle cell pain?
2. Has the patient ever been diagnosed with severe or recurrent acute chest syndrome?

If the answer is YES to either of these questions:

- For patients with Hemoglobin SS or S/beta^0 – thalassemia proceed to **section II** regarding patient counseling, as these patients may benefit from hydroxyurea.

- Patients with Hemoglobin S/beta$^+$ - thalassemia or Hemoglobin SC are potential candidates. Please call Dr. Lottenberg at 352-392-3000 for consultation.

Additional clinical considerations that may mean a patient is a candidate:

3. Does the patient require chronic narcotic therapy for control of sickle cell pain?
4. Does the patient have symptomatic anemia requiring periodic transfusion?
5. Has the patient had a stroke but cannot be transfused?
6. Has the patient had recurrence of other vaso-occlusive episodes (e.g. priapism)?

If the answer is YES to any of questions 3-6:
Please call Dr. Lottenberg at 352-392-3000 for consultation.

II. Information Session for Patient and Family: Weighing the benefits vs. harms of hydroxyurea therapy

1. Frequent painful episodes (crises) are associated with an increased risk for adverse outcomes
    - acute chest syndrome
    - multi-organ failure syndrome
    - hospital-related complications/infections
    - early mortality

2. Adult patients with recurrent acute chest syndrome
    - Risk for repeat episodes of acute chest syndrome
    - Risk for chronic pulmonary complications
    - Experience increased mortality compared to patients without acute chest syndrome

3. Hydroxyurea has been shown to be efficacious [results of the Multicenter Study of Hydroxyurea in Sickle Cell Anemia (MSH)]
    - Reduction in painful episodes
    - Reduction in the occurrence of acute chest syndrome
    - Reduction in frequency of hospitalizations
    - Reduction in transfusion requirement

4. Review the MSH 9-year follow up results
    - Reduction in mortality for patients taking hydroxyurea
    - No increased incidence of cancer for patients taking hydroxyurea

5. Review importance of compliance to therapy recommendations
    - Not all patients respond to hydroxyurea
    - Requirement to take medication on a daily basis
    - Requirement to adhere to prescribed clinical follow-up

6. Requirement for continuing contraception (women and men)
    - Possible teratogenicity of hydroxyurea

7. Review potential side-effects
    - Consequences of myelosuppression
    - Possible nausea, hair loss, increased skin/nail pigmentation, skin ulceration
    - Possible weight gain
    - Risk for cancer/leukemia uncertain but appears small
        - see item (4.) above
        - publications outside the MSH trial limited to 4 case reports - ? relationship to treatment
        - monitoring of MSH trial participants is continuing

If the patient decides to start hydroxyurea therapy proceed to Section III.

III. Initiation of Hydroxyurea Therapy

STEP 1: Baseline Laboratory Evaluation

1. Complete Blood Count with WBC differential and reticulocyte count
2. Hemoglobin electrophoresis (elevation of Hemoglobin F level is **NOT** a contraindication to treatment)
3. For women: Pregnancy test
4. Renal and liver function tests

STEP 2: Initiation and monitoring of therapy

1. Counsel patient regarding need for contraception (men and women) and careful follow up
2. Starting dosage (500 mg capsules): **15 mg/kg/day** [5-10 mg/kg/day if renal or hepatic dysfunction]
3. Prescribe folate 1 mg/day
4. Monitor CBC every 2 weeks
    - Maintain absolute neutrophil count ≥ 2,500/uL
    - Maintain platelets ≥ 95,000/uL
5. Monitor renal and liver function tests every 4 weeks during dose escalation
6. Escalate daily dose 500 - 1000 mg every 6-8 weeks [**maximum: 35 mg/kg/day if no evidence of toxicity**]. Note optimal dose may require alternating daily doses, e.g. 1000/1500 mg QOD.
7. Once desired effect is achieved blood counts and can be monitored every 4-8 weeks
8. If sub-optimal clinical response: Monitor red cell MCV and Hb F levels for evidence of laboratory response and compliance (recommended interval: every 6 - 8 weeks)

Endpoints for Dose Escalation

- reduction in sickle cell pain frequency and/or severity

    OR
- evidence of myelosuppression

IV. Lack of Clinical Response for Sickle Cell Pain Indication

1. Laboratory findings indicative of hydroxyurea effect:
    - Increased Hb F level
    - Increased red cell MCV
    - Increased hemoglobin level compared to baseline

2. Measures of compliance:
    - Pharmacy records
    - Pill counts
    - Patient diary
    - Increased red cell MCV

Certain patients will not have a clinical response to hydroxyurea even if compliant. There may or may not be any of the laboratory value changes indicated above. A trial period of 6-12 months of therapy with dose escalation as outlined is recommended prior to discontinuing therapy for lack of clinical response as described above.

PATIENT LOG FOR UF SICKLE CELL DISEASE HYDROXYUREA PROJECT

	NAME	CLINICAL PRACTICE TOOL USED (y/n)	DATE
1.	_____	_____	_____
2.	_____	_____	_____
3.	_____	_____	_____
4.	_____	_____	_____
5.	_____	_____	_____
6.	_____	_____	_____
7.	_____	_____	_____
8.	_____	_____	_____
9.	_____	_____	_____
10.	_____	_____	_____
11.	_____	_____	_____
12.	_____	_____	_____
13.	_____	_____	_____
14.	_____	_____	_____
15.	_____	_____	_____
16.	_____	_____	_____
17.	_____	_____	_____
18.	_____	_____	_____
19.	_____	_____	_____
20.	_____	_____	_____
21.	_____	_____	_____
22.	_____	_____	_____
23.	_____	_____	_____
24.	_____	_____	_____
25.	_____	_____	_____
26.	_____	_____	_____
27.	_____	_____	_____
28.	_____	_____	_____
29.	_____	_____	_____
30.	_____	_____	_____

Appendix B

SHANDS
at the University of Florida
Gainesville, Florida 32610

Physician's Orders

Patient Name: MR#:

Date	Time	Adult Sickle Cell Disease Pain Episode: Inpatient Admission Orders *page 1 of 3*
		(All orders with a ☐ must be checked to be activated)
		1. **Admit** to: ☐ Unit 74 ☐ Unit 55 ☐ Other: _____
		2. **Medical Diagnosis** Sickle Cell Pain Episode _____ **Condition:** ☐ Good ☐ Fair ☐ Serious ☐ Critical
		3. **Service:** _____
		Intern _____ Pager # _____
		Resident Physician _____ Pager # _____
		Attending Physician _____ Pager # _____
		4. **Contact:** Adult Sickle Cell Nurse Specialist, ext. 88026 and leave voicemail with patient name and
		room # for post admission follow-up.
		5. **Allergies:** ☐ NKDA ☐ Other: _____
		6. RN to Obtain and Record **Admission Height and Weight:** Ht – *inches* Wt – *kg*
		7. **Vital Signs:** VS with O_2 Sat check q4hr, VAS (0-10) Pain Score q4hr
		8. ☐ **Continuous pulse oximetry** – (required for basal PCA)
		9. **Notify House Officer if patient exhibits:**
		a) T greater than 38.5˚C
		b) R greater than 26 or less than 10
		c) O_2 sats less than 90% or pt's baseline
		d) Respiratory depression; call before administering naloxone (NARCAN)
		e) SBP greater than 170 or less than 90, DBP greater than 105 or less than 55
		f) HR greater than 120 or less than 50
		g) UOP less than 30 mL / hr
		h) inadequate pain relief
		10. **Diet:** _____ ☐ Encourage PO fluids
		11. **Activity:** ☐ Bedrest ☐ Bedrest with bathroom privileges ☐ Other: _____
		12. **Chest X-Ray:** ☐ 1 view ☐ PA / LAT Reason: _____
		13. **Admission Labs (if not drawn in ED):** ☐ CBC & Diff ☐ Reticulocyte count ☐ Renal Battery
		☐ _____ ☐ _____ ☐ _____
		14. ☐ **Incentive Spirometry** 3 times per hour while awake. Instruct patient on proper use.
		(continued on next page)

Distribution: Medical Record – Be sure to fax to Pharmacy.
Rev. 11/25/03

SHANDS
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Gainesville, Florida 32610

Physician's Orders

Patient Name: MR#:

Date	Time	Adult Sickle Cell Disease Pain Episode: Inpatient Admission Orders *page 2 of 3*
		(All orders with a ☐ must be checked to be activated)
		15. ☐ **Accurate I&O**
		16. ☐ **IVF (*hypotonic solution*):** D5$^1/_2$ NS + _____ mEq KCl @ _____ mL / hr x 24 hours, then
		D5$^1/_2$ NS @ 100 mL
		☐ **IVF (*hypotonic solution*):** Other _____
		17. **Medications:**
		Discontinue Hydroxyurea (if applicable)
		☐ docusate sodium (COLACE) 100 mg PO BID
		☐ folic acid 1 mg PO daily
		☐ diphenhydramine (BENADRYL) 25 mg PO q4hr PRN pruritis
		☐ promethazine (PHENERGAN) 25 mg IV q4hr PRN for N/V
		☐ MAALOX 15 - 30 mL PO q4hr PRN dyspepsia
		☐ senna 1 - 2 tabs PO at bedtime PRN constipation
		☐ Titrated naloxone (NARCAN) 0.04 mg / mL for respiratory depression (call MD before administration)
		Dilute 0.4 mg in 10 mL NS. Administer 0.5 mL IV then evaluate for resolution. Repeat q 2 min PRN.
		Only titrated naloxone (NARCAN) 0.04 mg / mL solution should be used to resolve respiratory depression
		because undiluted naloxone (NARCAN) will reverse all opioid analgesic effects.
		☐ Other:
		☐ Other:
		☐ Other:
		17a. **Medications:**
		Opioid loading dose prior to PCA initiation
		Timeframe: Administer immediately after initial pain assessment. If patient is uncomfortable with
		a VAS score greater than 3 and if patient has not received an opioid loading dose within the last
		60 minutes, then administer the following:
		☐ **morphine** _____ mg **IV** (0.1 mg / kg up to max 10 mg) for 1 dose
		OR
		If morphine contraindicated for patient, use hydromorphone dosing guidelines.
		☐ **hydromorphone (DILAUDID)** _____ mg **IV** (0.01 mg / kg up to max 2 mg) for 1 dose
		(continued on next page)

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Physician's Orders

Patient Name: MR#:

Date	Time	Adult Sickle Cell Disease Pain Episode: Inpatient Weaning / Transition Protocol – STEP 1 *page 1 of 2*
		(All orders with a ☐ must be checked to be activated)
		Adult SCD Pain Episode Weaning Protocol – The purpose of this weaning protocol is to provide adequate patient analgesia while transitioning the patient from parenteral PCA opioids to oral long-acting and short-acting opioids. This protocol is designed to follow the **Adult SCD Pain Episode: Admission Orders** in conjunction with the **Adult SCD Pain Episode Clinical Pathway**. Before this weaning protocol should be initiated, an adult SCD patient must have a VAS (0-10) Pain Score less than or equal to 3 or at pt's reported level of acceptable / functional pain VAS score for a minimum duration of 24 hours on PCA basal + demand. Generally, the weaning process has three steps / phases, thus the reason for three sets of **Adult SCD Pain Episode: Inpatient Weaning / Transition Orders**. The pt's individualized plan of care and associated time frames for weaning must be based upon his / her pain management outcomes. The desired weaning / transition outcomes are: 1) a pt's VAS Pain Score less than or equal to 3 or at pt's reported level of acceptable / functional pain VAS score and 2) patient discharge from the hospital.
		1. **Vital Signs:** Continue VS with O_2 sat check q4hr, VAS (0-10) Pain Score q4hr
		2. ☐ **Continuous Pulse Oximetry** (required for basal PCA).
		☐ Discontinue continuous pulse oximetry when basal rate of PCA discontinued.
		3. Call House Officer if patient exhibits:
		a) T greater than 38.5°C,
		b) R greater than 26 or less than 10,
		c) O_2 sats less than 90% or patient's baseline,
		d) Respiratory depression – call before administering naloxone (NARCAN),
		e) SBP greater than 170 or less than 90, DBP greater than 105 or less than 55,
		f) HR greater than 120 or less than 50,
		g) UOP less than 30 mL / hr,
		h) inadequate pain relief,
		i) excessive sedation
		4. **Diet:** _____ ☐ Encourage PO fluids
		5. **Activity:** _____
		6. **X-rays:** ☐ CXR ☐ Other: _____
		7. **Labs:** ☐ CBC & Diff q _____ ☐ Reticulocyte count q _____ ☐ Renal Battery q _____
		☐ _____ ☐ _____ ☐ _____
		8. **IVF** *(hypotonic solution)*: _____ @ _____ mL / hr ☐ Medlock
		9. Continue **Accurate I&O**
		10. Continue **Incentive Spirometry** 3 times per hour while awake. Instruct patient on proper use.
		(continued on next page)

SHANDS
at the University of Florida

The Clinical Pathway is a general guideline for the plan of care. Patient care continues to require individualization based on patient needs and response.

Patient Name: M.R. #

CLINICAL PATHWAY
PATH TITLE: Adult Sickle Cell Disease Pain Episode (DRG 395, LOS 4.4 Days)
SERVICE: Adult Medicine/Hematology/Oncology
ATTENDING: _____
ALLERGY ALERT: **Note all allergies and check to ensure patient receives no medication allergic to. Call service to obtain alternative medications.*

Interventions documented in patient's Medical Record.

CARE ELEMENT	PRESENTATION PHASE
CARE UNIT	• ED
CONSULTS	• Sickle Cell Nurse Specialist, ext. 88026 and leave voicemail with patient name and room #
TESTS/LABS	• **X-rays:** CXR • **Labs:** *Min eval* – CBC & Diff, Retic count, Renal Battery. *Add. Eval, if suggested by H&P:* Urine C&S, ECG, ABG, Blood cultures if T>38.5° C
ASSESSMENTS **Notify MD for vital signs outside the following parameters:** • Temp above 38.5°C • HR - 50-120 • UOP below 30 mL/hr • VAS greater than 3 or patient's acceptable/ functional score • O2 Sats greater than 90% or pt's baseline • SBP - 90-17(• DBP - 55-10! • R – 10-26 • Excessive sedation • Inadequate analgesia	• Baseline VS, O2 Sats, VAS (0-10) pain score then q 1hr assessments. • Believe pt's reported level of pain. Assess for pain intensity (VAS), location, duration, aggravating and alleviating factors. • Cont. pulse ox (required for basal PCA) • Accurate I&O • Assess hydration status q 12 hrs • Check skin integrity q shift
TREATMENTS	• **Hypotonic IVF**: Maintenance IVF 1 L bolus @250 mL/hr, then decrease rate as ordered • IS 3x per hr W/A • O_2 via N/C PRN
MEDICATIONS	• **Pain management:** - Opiod loading dose(IV preferred) PO or SC if no IV access - Morphine (use DILAUDID if morphine contraindicated) PCA basal + demand q 15 min lockout. Titrate to keep VAS pain score ≤ 3. • PRN meds for comfort, side effects • D/C Hydroxyurea (if applicable)
PAIN/SYMPTOM CONTROL	• If inadequate pain relief after 4 hrs, anticipate admission to Unit 74 or 55. • If adequate pain relief after 4 hrs, anticipate D/C from ED with 10 day supply of long & short acting opiods & F/U appt. in Adult Hem/Onc Outpt. Clinic within 10 days. • Monitor, report & treat opiod side effects
ACTIVITY	• Bedrest w/ BRP
NUTRITION	• Diet as ordered • Encourage PO fluids if no IV access
PSYCHOSOCIAL/ COMMUNICATION	• Identify communication barriers • Assess mood, affect, perceived stress,adaptive behavior, coping skills/ support • Involve pt/family in care, decision-making, and realistic goal setting
INDIVIDUAL Needs/Problems	• Assess for unmet needs. Provide support and make appropriate referrals.
D/C EDUCATION PLANNING	• Educate on possible precipitating factors • F/U appt. in Adult Hem/Onc Outpt. Clinic within 10 days. • Pt to return to ED if has increased pain, chest pain, SOB, T>38.5°C
OUTCOMES – Document if met/not met on Clinical Pathway Outcome Tool	

SHANDS
at the University of Florida

CLINICAL PATHWAY
PATH TITLE: Adult Sickle Cell Disease Pain Episode (DRG 395, LOS 4.4 Days)
SERVICE: Adult Medicine/Hematology/Oncology
ATTENDING:

Patient Name: M.R. #

CARE ELEMENT	WEANING/ TRANSITION STEP 1 PHASE	WEANING/ TRANSITION STEP 2 PHASE
CARE UNIT	• Unit 74 or 55	• Unit 74 or 55
CONSULTS	•	
TESTS/LABS	**Labs:** CBC & Diff	**Labs:** CBC & Diff
ASSESSMENTS **Notify MD for vital signs outside the following parameters:** • Temp above 38.5°C • HR - 50-120 • UOP below 30 mL/hr • VAS greater than 3 or patient's acceptable/ functional score • O2 Sats greater than 90% or pt's baseline • SBP - 90-17(• DBP - 55-10 • R – 10-26 • Excessive sedation • Inadequate analgesia	• VS, O2 sats, VAS (0-10) pain score, sedation level q 4hrs • Cont. pulse ox (required for basal PCA) • I &O • Assess hydration status q 12 hrs • Check skin integrity q shift	• VS, O2 sats, VAS (0-10) pain score, sedation level q 4hrs • I &O • Assess hydration status q 12 hrs • Check skin integrity q shift
TREATMENTS	• **Hypotonic IVF:** Maintenance IVF as ordered • IS 3x per hr W/A • • O_2 via N/C PRN	• **Hypotonic IVF:** Decrease maintenance IVF rate with possible conversion to Medlock, if taking PO well • IS 3x per hr W/A • O_2 via N/C PRN
MEDICATIONS	• **Pain management:** - Start PO long acting opiod (Morphine SR or Oxycontin) while pt on basal + demand PCA - D/C basal PCA 12 – 24 hrs after start of PO long acting opiod - NSAIDs (optional) if tolerated • PRN meds for side effects, increase comfort	• **Pain management:** - Continue Demand PCA - Start short acting opiod (Oxycodone) PO q 4h PRN for breakthrough pain - NSAIDs (optional) if tolerated • Administer PRN meds to control side effects, increase comfort
PAIN/SYMPTOM CONTROL	• Incorporate non-pharmacologic pain management techniques such as relaxation, imagery, music, etc. • Monitor, report & treat opiod side effects • When basal component PCA D/C'd & pt. exhibits adequate analgesia from PO long acting opiods + demand PCA for min. duration of 24 hrs, RN to notify MD to initiate **Adult Sickle Cell Disease Pain Episode: Weaning / Transition Protocol – Step 2.**	• Incorporate non-pharmacologic pain management techniques. • Monitor, report & treat opiod side effects • When pt. has adequate analgesia with demand component of PCA, long acting and short acting PO opoids for min. duration of 24 hrs, RN to notify MD to initiate • **Adult Sickle Cell Disease Pain Episode: Weaning / Transition Protocol – Step 3.**
ACTIVITY	• As tolerated	• As tolerated
NUTRITION	• Diet as ordered • Encourage PO fluids	• Diet as ordered • Encourage PO fluids
PSYCHOSOCIAL/ COMMUNICATION	• Assess pt's mood, affect, perceived stress levels, adaptive behavior, coping skills and support systems qd • Involve pt/family in care, decision-making, and realistic goal setting	• Assess pt's mood, affect, perceived stress levels, adaptive behavior, coping skills and support systems qd • Involve pt/family in care, decision-making, and realistic goal setting
INDIVIDUAL Needs/Problems	• Assess for unmet needs. Provide support and make appropriate interdisciplinary &/or community referrals.	• Assess for unmet needs. Provide support and make appropriate interdisciplinary &/or community referrals.
D/C EDUCATION PLANNING	• Address lifestyle changes - no smoking, medication compliance, adequate hydration, health maintenance • Document education completed on IPFER • Begin D/C planning assessment (transportation and destination arrangements)	• Address lifestyle changes - no smoking, medication compliance, adequate hydration, health maintenance • Document education completed on IPFER • Continue D/C planning assessment (securing D/C meds, DME if needed)
OUTCOMES – Document if met/not met on Clinical Pathway Outcome Tool		

Appendix B

SHANDS
at the University of Florida
Gainesville, Florida 32610

Physician's Orders

Patient Name: MR#:

Date	Time	Adult Sickle Cell Disease Pain Episode: Inpatient Admission Orders *page 1 of 3*
		(All orders with a ☐ must be checked to be activated)
		1. **Admit** to: ☐ Unit 74 ☐ Unit 55 ☐ Other: _____
		2. **Medical Diagnosis** Sickle Cell Pain Episode _____ **Condition:** ☐ Good ☐ Fair ☐ Serious ☐ Critical
		3. **Service:** _____
		Intern _____ Pager # _____
		Resident Physician _____ Pager # _____
		Attending Physician _____ Pager # _____
		4. **Contact:** Adult Sickle Cell Nurse Specialist, ext. 88026 and leave voicemail with patient name and
		room # for post admission follow-up.
		5. **Allergies:** ☐ NKDA ☐ Other: _____
		6. RN to Obtain and Record **Admission Height and Weight:** Ht – *inches* Wt – *kg*
		7. **Vital Signs:** VS with O_2 Sat check q4hr, VAS (0-10) Pain Score q4hr
		8. ☐ **Continuous pulse oximetry** – (required for basal PCA)
		9. **Notify House Officer if patient exhibits:**
		a) T greater than 38.5˚C
		b) R greater than 26 or less than 10
		c) O_2 sats less than 90% or pt's baseline
		d) Respiratory depression; call before administering naloxone (NARCAN)
		e) SBP greater than 170 or less than 90, DBP greater than 105 or less than 55
		f) HR greater than 120 or less than 50
		g) UOP less than 30 mL / hr
		h) inadequate pain relief
		10. **Diet:** _____ ☐ Encourage PO fluids
		11. **Activity:** ☐ Bedrest ☐ Bedrest with bathroom privileges ☐ Other: _____
		12. **Chest X-Ray:** ☐ 1 view ☐ PA / LAT Reason: _____
		13. **Admission Labs (if not drawn in ED):** ☐ CBC & Diff ☐ Reticulocyte count ☐ Renal Battery
		☐ _____ ☐ _____ ☐ _____
		14. ☐ **Incentive Spirometry** 3 times per hour while awake. Instruct patient on proper use.
		(continued on next page)

Distribution: Medical Record – Be sure to fax to Pharmacy.
Rev. 11/25/03

SHANDS
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Gainesville, Florida 32610

Physician's Orders

Patient Name: MR#:

Date	Time	Adult Sickle Cell Disease Pain Episode: Inpatient Admission Orders *page 2 of 3*
		(All orders with a ☐ must be checked to be activated)
		15. ☐ **Accurate I&O**
		16. ☐ **IVF (*hypotonic solution*):** D5$^1/_2$ NS + _____ mEq KCl @ _____ mL / hr x 24 hours, then
		D5$^1/_2$ NS @ 100 mL
		☐ **IVF (*hypotonic solution*):** Other _____
		17. **Medications:**
		Discontinue Hydroxyurea (if applicable)
		☐ docusate sodium (COLACE) 100 mg PO BID
		☐ folic acid 1 mg PO daily
		☐ diphenhydramine (BENADRYL) 25 mg PO q4hr PRN pruritis
		☐ promethazine (PHENERGAN) 25 mg IV q4hr PRN for N/V
		☐ MAALOX 15 - 30 mL PO q4hr PRN dyspepsia
		☐ senna 1 - 2 tabs PO at bedtime PRN constipation
		☐ Titrated naloxone (NARCAN) 0.04 mg / mL for respiratory depression (call MD before administration)
		Dilute 0.4 mg in 10 mL NS. Administer 0.5 mL IV then evaluate for resolution. Repeat q 2 min PRN.
		Only titrated naloxone (NARCAN) 0.04 mg / mL solution should be used to resolve respiratory depression
		because undiluted naloxone (NARCAN) will reverse all opioid analgesic effects.
		☐ Other:
		☐ Other:
		☐ Other:
		17a. **Medications:**
		Opioid loading dose prior to PCA initiation
		Timeframe: Administer immediately after initial pain assessment. If patient is uncomfortable with
		a VAS score greater than 3 and if patient has not received an opioid loading dose within the last
		60 minutes, then administer the following:
		☐ **morphine** _____ mg **IV** (0.1 mg / kg up to max 10 mg) for 1 dose
		OR
		If morphine contraindicated for patient, use hydromorphone dosing guidelines.
		☐ **hydromorphone (DILAUDID)** _____ mg **IV** (0.01 mg / kg up to max 2 mg) for 1 dose
		(continued on next page)

SHANDS
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Physician's Orders

Patient Name: MR#:

Date	Time	Adult Sickle Cell Disease Pain Episode: Inpatient Weaning / Transition Protocol – STEP 1 *page 1 of 2*
		(All orders with a ☐ must be checked to be activated)
		Adult SCD Pain Episode Weaning Protocol – The purpose of this weaning protocol is to provide adequate patient analgesia while transitioning the patient from parenteral PCA opioids to oral long-acting and short-acting opioids. This protocol is designed to follow the **Adult SCD Pain Episode: Admission Orders** in conjunction with the **Adult SCD Pain Episode Clinical Pathway**. Before this weaning protocol should be initiated, an adult SCD patient must have a VAS (0-10) Pain Score less than or equal to 3 or at pt's reported level of acceptable / functional pain VAS score for a minimum duration of 24 hours on PCA basal + demand. Generally, the weaning process has three steps / phases, thus the reason for three sets of **Adult SCD Pain Episode: Inpatient Weaning / Transition Orders**. The pt's individualized plan of care and associated time frames for weaning must be based upon his / her pain management outcomes. The desired weaning / transition outcomes are: 1) a pt's VAS Pain Score less than or equal to 3 or at pt's reported level of acceptable / functional pain VAS score and 2) patient discharge from the hospital.
		1. **Vital Signs:** Continue VS with O_2 sat check q4hr, VAS (0-10) Pain Score q4hr
		2. ☐ **Continuous Pulse Oximetry** (required for basal PCA).
		☐ Discontinue continuous pulse oximetry when basal rate of PCA discontinued.
		3. Call House Officer if patient exhibits:
		a) T greater than 38.5°C,
		b) R greater than 26 or less than 10,
		c) O_2 sats less than 90% or patient's baseline,
		d) Respiratory depression – call before administering naloxone (NARCAN),
		e) SBP greater than 170 or less than 90, DBP greater than 105 or less than 55,
		f) HR greater than 120 or less than 50,
		g) UOP less than 30 mL / hr,
		h) inadequate pain relief,
		i) excessive sedation
		4. **Diet:** _____ ☐ Encourage PO fluids
		5. **Activity:** _____
		6. **X-rays:** ☐ CXR ☐ Other: _____
		7. **Labs:** ☐ CBC & Diff q _____ ☐ Reticulocyte count q _____ ☐ Renal Battery q _____
		☐ _____ ☐ _____ ☐ _____
		8. **IVF** *(hypotonic solution)*: _____ @ _____ mL / hr ☐ Medlock
		9. Continue **Accurate I&O**
		10. Continue **Incentive Spirometry** 3 times per hour while awake. Instruct patient on proper use.
		(continued on next page)

SHANDS
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The Clinical Pathway is a general guideline for the plan of care. Patient care continues to require individualization based on patient needs and response.

Patient Name: M.R. #

CLINICAL PATHWAY
PATH TITLE: Adult Sickle Cell Disease Pain Episode (DRG 395, LOS 4.4 Days)
SERVICE: Adult Medicine/Hematology/Oncology
ATTENDING: _____
ALLERGY ALERT: **Note all allergies and check to ensure patient receives no medication allergic to. Call service to obtain alternative medications.*

Interventions documented in patient's Medical Record.

CARE ELEMENT	PRESENTATION PHASE
CARE UNIT	• ED
CONSULTS	• Sickle Cell Nurse Specialist, ext. 88026 and leave voicemail with patient name and room #
TESTS/LABS	• **X-rays:** CXR • **Labs:** *Min eval* – CBC & Diff, Retic count, Renal Battery. *Add. Eval, if suggested by H&P:* Urine C&S, ECG, ABG, Blood cultures if T>38.5° C
ASSESSMENTS **Notify MD for vital signs outside the following parameters:** • Temp above 38.5°C • HR - 50-120 • UOP below 30 mL/hr • VAS greater than 3 or patient's acceptable/ functional score • O2 Sats greater than 90% or pt's baseline • SBP - 90-17(• DBP - 55-10! • R – 10-26 • Excessive sedation • Inadequate analgesia	• Baseline VS, O2 Sats, VAS (0-10) pain score then q 1hr assessments. • Believe pt's reported level of pain. Assess for pain intensity (VAS), location, duration, aggravating and alleviating factors. • Cont. pulse ox (required for basal PCA) • Accurate I&O • Assess hydration status q 12 hrs • Check skin integrity q shift
TREATMENTS	• **Hypotonic IVF**: Maintenance IVF 1 L bolus @250 mL/hr, then decrease rate as ordered • IS 3x per hr W/A • O_2 via N/C PRN
MEDICATIONS	• **Pain management:** - Opiod loading dose(IV preferred) PO or SC if no IV access - Morphine (use DILAUDID if morphine contraindicated) PCA basal + demand q 15 min lockout. Titrate to keep VAS pain score ≤ 3. • PRN meds for comfort, side effects • D/C Hydroxyurea (if applicable)
PAIN/SYMPTOM CONTROL	• If inadequate pain relief after 4 hrs, anticipate admission to Unit 74 or 55. • If adequate pain relief after 4 hrs, anticipate D/C from ED with 10 day supply of long & short acting opiods & F/U appt. in Adult Hem/Onc Outpt. Clinic within 10 days. • Monitor, report & treat opiod side effects
ACTIVITY	• Bedrest w/ BRP
NUTRITION	• Diet as ordered • Encourage PO fluids if no IV access
PSYCHOSOCIAL/ COMMUNICATION	• Identify communication barriers • Assess mood, affect, perceived stress,adaptive behavior, coping skills/ support • Involve pt/family in care, decision-making, and realistic goal setting
INDIVIDUAL Needs/Problems	• Assess for unmet needs. Provide support and make appropriate referrals.
D/C EDUCATION PLANNING	• Educate on possible precipitating factors • F/U appt. in Adult Hem/Onc Outpt. Clinic within 10 days. • Pt to return to ED if has increased pain, chest pain, SOB, T>38.5°C
OUTCOMES – Document if met/not met on Clinical Pathway Outcome Tool	

SHANDS
at the University of Florida

CLINICAL PATHWAY
PATH TITLE: Adult Sickle Cell Disease Pain Episode (DRG 395, LOS 4.4 Days)
SERVICE: Adult Medicine/Hematology/Oncology
ATTENDING:

Patient Name: M.R. #

CARE ELEMENT	WEANING/ TRANSITION STEP 1 PHASE	WEANING/ TRANSITION STEP 2 PHASE
CARE UNIT	• Unit 74 or 55	• Unit 74 or 55
CONSULTS	•	
TESTS/LABS	**Labs:** CBC & Diff	**Labs:** CBC & Diff
ASSESSMENTS **Notify MD for vital signs outside the following parameters:** • Temp above 38.5°C • HR - 50-120 • UOP below 30 mL/hr • VAS greater than 3 or patient's acceptable/ functional score • O2 Sats greater than 90% or pt's baseline • SBP - 90-17(• DBP - 55-10 • R – 10-26 • Excessive sedation • Inadequate analgesia	• VS, O2 sats, VAS (0-10) pain score, sedation level q 4hrs • Cont. pulse ox (required for basal PCA) • I &O • Assess hydration status q 12 hrs • Check skin integrity q shift	• VS, O2 sats, VAS (0-10) pain score, sedation level q 4hrs • I &O • Assess hydration status q 12 hrs • Check skin integrity q shift
TREATMENTS	• **Hypotonic IVF:** Maintenance IVF as ordered • IS 3x per hr W/A • • O_2 via N/C PRN	• **Hypotonic IVF:** Decrease maintenance IVF rate with possible conversion to Medlock, if taking PO well • IS 3x per hr W/A • O_2 via N/C PRN
MEDICATIONS	• **Pain management:** - Start PO long acting opiod (Morphine SR or Oxycontin) while pt on basal + demand PCA - D/C basal PCA 12 – 24 hrs after start of PO long acting opiod - NSAIDs (optional) if tolerated • PRN meds for side effects, increase comfort	• **Pain management:** - Continue Demand PCA - Start short acting opiod (Oxycodone) PO q 4h PRN for breakthrough pain - NSAIDs (optional) if tolerated • Administer PRN meds to control side effects, increase comfort
PAIN/SYMPTOM CONTROL	• Incorporate non-pharmacologic pain management techniques such as relaxation, imagery, music, etc. • Monitor, report & treat opiod side effects • When basal component PCA D/C'd & pt. exhibits adequate analgesia from PO long acting opiods + demand PCA for min. duration of 24 hrs, RN to notify MD to initiate **Adult Sickle Cell Disease Pain Episode: Weaning / Transition Protocol – Step 2.**	• Incorporate non-pharmacologic pain management techniques. • Monitor, report & treat opiod side effects • When pt. has adequate analgesia with demand component of PCA, long acting and short acting PO opoids for min. duration of 24 hrs, RN to notify MD to initiate • **Adult Sickle Cell Disease Pain Episode: Weaning / Transition Protocol – Step 3.**
ACTIVITY	• As tolerated	• As tolerated
NUTRITION	• Diet as ordered • Encourage PO fluids	• Diet as ordered • Encourage PO fluids
PSYCHOSOCIAL/ COMMUNICATION	• Assess pt's mood, affect, perceived stress levels, adaptive behavior, coping skills and support systems qd • Involve pt/family in care, decision-making, and realistic goal setting	• Assess pt's mood, affect, perceived stress levels, adaptive behavior, coping skills and support systems qd • Involve pt/family in care, decision-making, and realistic goal setting
INDIVIDUAL Needs/Problems	• Assess for unmet needs. Provide support and make appropriate interdisciplinary &/or community referrals.	• Assess for unmet needs. Provide support and make appropriate interdisciplinary &/or community referrals.
D/C EDUCATION PLANNING	• Address lifestyle changes - no smoking, medication compliance, adequate hydration, health maintenance • Document education completed on IPFER • Begin D/C planning assessment (transportation and destination arrangements)	• Address lifestyle changes - no smoking, medication compliance, adequate hydration, health maintenance • Document education completed on IPFER • Continue D/C planning assessment (securing D/C meds, DME if needed)
OUTCOMES – Document if met/not met on Clinical Pathway Outcome Tool		