# UCLA UCLA Electronic Theses and Dissertations

# Title

Hospitalization patterns and emergency department use for youth and young adults growing older with sickle cell disease.

Permalink https://escholarship.org/uc/item/94f618vg

Author Jones, Jenna

**Publication Date** 2014

Peer reviewed|Thesis/dissertation

University of California Los Angeles

Hospitalization patterns and emergency department use for youth and young adults growing older with sickle cell disease.

A dissertation submitted in partial satisfaction of the

requirements for the degree Doctor of Philosophy

in Health Services

by

Jenna Marie Jones

© Copyright by

Jenna Marie Jones

# ABSTRACT OF DISSERTAION

# Hospitalization patterns and emergency department use for youth and young adults growing older with sickle cell disease.

by

Jenna Marie Jones Doctor of Philosophy in Health Services University of California, Los Angeles, 2014 Professor Jack Needleman, Chair

**Introduction:** Due to advances in medical knowledge and technology, life expectancy has increased for many child-onset complex chronic conditions including sickle cell disease (SCD). As a result of living longer and reaching age-dependent cut-offs for insurance eligibility, a greater number of young adult SCD survivors may experience insurance loss, loss of access to health care and consequently have higher adverse health events and greater utilization of hospital services. This is a possible consequence for individuals dependent on public programs such as the California Children's Services (CCS) program in which eligibility ends on the 21<sup>st</sup> birthday. **Purpose:** The primary purpose of this study was to examine variation in hospital and emergency care use between youth (ages 14-17 years) and young adults (ages 18-20 years and ages 21-26 years). Secondarily, the purpose was to examine variations in utilization by social disadvantage

as defined by community poverty level, insurance status, and travel distance from home to nearest hospital.

**Data and Methods:** This retrospective quantitative analysis utilized confidential patient level discharge data (PDD) and emergency department (EDD/ASCD) patient encounter data collected by the Office of Statewide Planning & Development (OSHPD) from 2006-2011. Patients were included in the study population if they had either a primary or secondary ICD-9 code of sickle cell anemia, sickle cell thalassemia with crisis, and sickle cell thalassemia without crisis. Some of these patients had hospitalizations that were not coded for SCD. Hospitalizations with matching patient identifiers to hospitalizations selected with SCD were also included. Patients were categorized according to age group based upon age and relative eligibility to CCS/Medicaid services. Multi-level zero-truncated negative binomial regressions, generalized estimating equations with negative binomial link, and multilevel logistic regressions were performed to assess the association of age and socio-economic factors on count of index hospitalizations, readmissions within 30 days, length of stay (LOS), and count of ED visits after controlling for patient demographics, hospital level characteristics, or zip code level poverty status. **Results:** 1,825 patients were identified accounting for 13,257 hospitalizations in the PDD dataset and 27,001 ED visits representing 2,314 patients in the EDD dataset. Twenty-five percent of index hospitalizations were followed by at least one readmission within 30 days of last discharge. The population hospitalized had a mean LOS of 6.2 days. The number of hospitalizations and visits steadily increased between age groups 14-17 and 18-20 with the greatest increase occurring after age 21. Over half of all SCD hospitalizations (56%) and ED visits (66%) during the six year period were for patients ages 21-26. Statistically significant

differences in number of index admissions were observed between patients aged 21-26

iii

[IRR=1.60; 95% CI: 1.34-1.95; p value=0.00] and 14-17 when adjusting for individual and contextual factors. Age group 21-26 was associated with higher odds of readmission [OR= 1.14; 95% CI: 0.93-1.40; p value=0.02], longer LOS [IRR=1.02; 95% CI: 1.01-1.03; p value=0.00], and increased number of ED visits [IRR=2.27; 95% CI: 1.88-2.75; p value=0.00] relative to (which age group). Some SES factors were significantly associated with all outcomes. Lack of insurance was associated with significantly lower predicted index hospitalizations [IRR =0.34; 95% CI: 0.27-0.44; p value=0.00], readmission [OR= 0.64; 95% CI: 0.48-0.88; p value=0.05], LOS [IRR= 0.96; 95% CI: 0.94-0.98, p value=0.00], and ED visits [IRR =035; 95% CI: 0.30-0.44; p value=0.00] than those with Medicaid/other government insurance. Residing in zip codes with a higher concentration of poverty was associated with higher odds of a readmission [OR= 0.80; 95% CI: 0.65-0.99; p value=0.05].

**Conclusions:** Hospitalizations, ED visits and LOS increases with age among SCD patients. Lack of insurance was associated with decreased hospitalizations, ED visits and shorter LOS. Understanding drivers that influence higher hospitalization rates, longer LOS, and greater ED care seeking behavior as youth grow older should be further explored. Drivers may include increasing severity of illness, delays in accessing primary care, growing difficulties in selfmanagement as an adolescent enters into adulthood, and changes in access to care resulting in losing insurance coverage for specialists. The dissertation of Jenna Marie Jones is approved.

Nadereh Pourat

Moira Inkelas

David Zingmond

Jack Needleman, Committee Chair

University of California, Los Angeles

# DEDICATION

To my parents and grandmother

Your hard work and support made my hard work possible.

# Table of Contents

Dissertation Components	Page Number
Title Page	NA
Copyright Page	NA
Abstract	ii
Committee Page	V
Dedication Page	vi
Acknowledgements	xiii
Vita	xiv
Chapter 1:	
Introduction	1
Chapter 2: Background and Literature Review	4
2.1 Defining Sickle Cell Disease as a Special Health Care Need	4
2.2 Specialized Health Insurance Programs (California Children's Service	es)5
2.3 Link Insurance and Utilization/Access for youth with SHCN	6
Chapter 3: Overall Conceptual Model	13
3.1 Measurable Contextual Level Variables	15
<ul><li>3.2 Measurable Individual Level Variables</li><li>3.3 Measureable Utilization of Personal Health Services</li></ul>	16
Chapter 4: Research Questions	20
4.1 Age-Related Research Questions and Related Hypotheses	20
4.2 Hypotheses for Socio-Economic Status Research Question	21
Chapter 5: Data and Measurement	24
5.1. California Office of Statewide Health Planning & Development	
(OSHPD) data sets	24

5.2 American Community Survey25
5.3 Sample Selection
5.4 Dependent Variables
5.5 Independent Variables: Primary Predictor of Interest
5.6 Independent Variables: Control Covariates
Chapter 6: Empirical Methods
6.1 Statistical Analyses
6.2. Sensitivity Analysis in count of Index and ED visit models
6.3 Analytical Model Illustrations
Chapter 7: Results
7.1 General Characteristics of Patients, Hospitalizations, and ED Visits
7.1.1 Descriptive Analysis
7.2 Count of Index Hospitalization
7.2.1 Descriptive Analyses
7.2.2 Adjusted Association of Index Hospitalizations with Age and SES78
7.2.3 Count of Index Hospitalization Sensitivity Analysis
7.3 Thirty Day Readmission84
7.3.1 Descriptive Analyses
7.3.2 Regression Adjusted Association of Thirty Day Readmission
7.4 Length of Stay
7.4.1 Descriptive Analyses
7.4.2 Regression Adjusted Association of Length of Stay with
Age and SES93
7.5 ED Utilization
7.5.1 Descriptive Analysis97
7.5.2 Regression Adjusted Association of ED visits with Age and SES

7.5.3 Count of ED visits Sensitivity Analysis	100
Chapter 8: Discussion and Conclusion	105
8.1 Principal Results	105
8.2 Comparisons to Previous Literature	109
8.3 Study Limitations and Caveats	110
8.3.1 Use of Administrative Data and Omitted Variables	110
8.3.2 Insurance Classification	111
8.3.3 Hospital Type Classification	112
8.3.4 Missing Denominator	112
8.3.5 Missing Data	113
8.3.6 Attribution Errors with Diagnosis Codes	114
8.4.7 Severity of Illness	115
8.4 Significance of Research	115
8.4.1 Research Questions	116
8.5 Practice and Policy Implications	116
8.6 Future Work	118
Appendix A: Additional Tables and Figures	120
Appendix B: Literature Review	128
References	150

#### List of Tables

- Table 1: ICD-9-CM List and Description
- Table 2: Most Frequently Reported Procedures (Full PDD and EDD Sample)
- Table 3: List of Original PDD OSHPD Variables Selected for Dissertation Analysis.
- Table 4: List of Original EDD OSHPD Variables Selected for Dissertation Analysis.

Table 5: Summary of Variables Included by Statistical Model

Table 6: Descriptive Summary of Hospitalizations and Demographicsbetween 2006 and 2011, at Hospitalization Level. (N=13,257)

Table 7: Patient Characteristics of Excluded Hospitalizations (n=1,025).

- Table 8: Age Group by Insurance at Hospitalization Level (sample size by age (percent by age)).
- Table 9: Descriptive Statistics of Hospitalizations, Poverty, Distance, and Switching

   by Age Group.
- Table 10: Descriptive Summary of Emergency DepartmentUtilization between 2006 and 2011 at Visit Level. (N=24,890)
- Table 11: Patient Characteristics of Excluded ED Visits (n=1,295).
- Table 12: Age Group by Insurance (sample size by age( percent by age)) at ED

   Visit Level.
- Table 13: ED Descriptive Statistics Poverty, Distance, and Switching by Age Group.
- Table 14: Descriptive Summary of Inpatient Utilization between 2006and 2011 at Individual Level (Index Analysis (N=1,825))

- Table 15: Zero-Truncated Negative Binomial Adjusted Associations: Count of

   Index Hospitalizations and Sensitivity Analysis
- Table 16: Descriptive Summary Between 2006 and 2011 at Index Hospitalization Level. (Readmission Analysis (N=8,203))
- Table 16b: Descriptive Summary of Between 2006 and 2011 and Readmission Level (N=5,054).
- Table 17: Multi-Level Logistic Regression with Cluster Correction: Thirty Day Readmission
- Table 18: Generalized Estimating Equation Regression Adjusted Associations:

   Length of Stay
- Table 19: Descriptive Summary between 2006 and 2011 at Patient Level (ED Analysis (N=2,314)).
- Table 20: Zero-Truncated Negative Binomial Adjusted Associations: Count of ED Visits and Sensitivity Analysis
- Table 21: Summary of Main Results:
- Appendix B: Literature Review

# List of Figures

- Figure 1: Adaptive Health Utilization Model by Contextual and Individual Level
- Figure 2: Flow Chart of Inclusion/Exclusion Sample Selection Process
- Figure 3: Correlation Matrix for variables included in model of Count of Index Hospitalizations
- Figure 4: Correlation Matrix variables included in model of 30 Day Readmission Model
- Figure 5: Correlation Matrix variables included in model of Length of Stay Model
- Figure 6: Correlation Matrix variables included in model of ED Visits Model
- Figure 7: Analytic Model for Count of Index Hospitalizations
- Figure 8: Analytic Model for 30 Day Readmissions
- Figure 9: Analytic Model for Length of Stay
- Figure 10: Analytic Model for Count of ED Visits
- Figure 11: NLMIXED Syntax for Count Models

#### ACKNOWLEDGMENTS

I would like to thank my dissertation chair, Dr. Jack Needleman, for his mentorship and support in developing this project. I am thankful for his dedication in training me through the completion of this dissertation and career advice. I would also like to thank my mentor, Dr. Nadereh Pourat, for taking me under her wing very early in my graduate school experience, training me, and providing timely and appropriate advice that I will carry with me throughout my career. For their help in planning, developing and executing this project, I would also like to thank Dr. Alice Kuo, Dr. Moira Inkelas, and Dr. David Zingmond.

In addition to my dissertation committee members, I would also like to thank the staff of the Office of Statewide Planning and Development for providing the data. I want to thank Rachel Louie for her statistical support.

I am grateful for Dr. Susan Ettner and the Clinical and Translational Science Institute (CTSI) TL1 Translational Science Fellowship for providing opportunities to share my research and gain professional experience. Part of this work is funded by NIH/National Center for Advancing Translational Science UCLA CTSI Grant Number TL1TR000121. Part of this work is funded by the UCLA Graduate Division Dissertation Year Fellowship Award (2013-2014).

# **EDUCATION**

Bachelor of Arts, Occidental College, Los Angeles, CA □ Major: Biology. December 2005

Masters of Public Health: Drexel University, Philadelphia, PA Emphasis: Health Management and Policy, June 2009

# **TEACHING EXPERIENCE**

Summer 2013 Part-Time Faculty Professor California State University. Los Angeles Public Health 440 The Health Care Delivery System. A one semester course introducing undergraduate students to topics in health care delivery.

Fall 2011 and Winter 2012

**Teaching Assistant** University of California, Los Angeles

Health Services 200 A & B Introduction to Health Care Organization and Finance. A two quarter course introducing master's and doctoral level students to topics in health care delivery. Held discussion sections, developed grading rubrics and graded assignments. Professors: E Richard Brown, PhD and Arturo Vargas-Bustamante, PhD

# **EMPLOYMENT HISTORY**

Graduate Student Researcher, UCLA Center for Health Policy Research Los Angeles, CA SAS and STATA programming, data analyses; planning, organizing and summarizing output from data analyses; assist with interpretation of data; draft literature reviews and papers for publication, creating tables and graphs; assist with the development of presentation materials.

Student Consultant, WellNow; Trevose, PA

Research and provide evidence of the cost-effectiveness of implementing a worksite wellness program in client's business operations. Recommending cost-savings opportunities based off of employee lifestyle claims data.

Public Policy and Advocacy Intern, National Multiple Sclerosis Society June 2008-September 2008 Philadelphia, PA Head of an insurance initiative project to assist the organization's clients with health care insurance issues including

maintaining insurance, understanding benefits, and making appeals; created policy briefs and white papers

Intern, Esperanza Health Center Philadelphia PA Worked with the Executive Director and Financial Manager to develop a strategic plan for the health center. This plan was submitted as part of their continuing grant application for their 330 (e) Federal Grant.

November 2009-July 2012

June 2008-June 2009

January 2008-May 2008

## **RESEARCH INTEREST**

Health care delivery, health insurance, utilization and access to health services, disparities, adolescent and child health care delivery, cost-effectiveness analysis.

## PUBLICATIONS AND PRESENTATIONS

N. Pourat and J. Jones. The role of insurance, income, and affordability on HPV vaccination. *The American Journal of Managed Care*. June 2012 (Publication)

Pourat N, Martinez AE, Jones, JM, Gregory KD, Korst L, Kominski GF. Costs of Gestational Hypertensive Disorders in California: Hypertension, Preeclampsia, and Eclampsia. Los Angeles (CA): UCLA Center for Health Policy Research; 2013. (Report)

J. Jones. and N. Pourat. Relationship between medical home and health care transition preparation for young adults ever diagnosed with a special health care condition. (Submitted manuscript in review)

Meng Y. Diamant A. Jones J. et. al. Can disease management programs improve diabetes care and reduce disparities for Medicaid Fee-for-Service beneficiaries? (Manuscript)

AcademyHealth Annual Research Meeting Child Health Service Research Meeting 2011 Healthcare transition preparation impact on future health Care Needs: implications for medical home model for young adults with special health care *needs* (Oral)

American Public Health Association Annual Meeting & Exposition 2010 Financial and nonfinancial barriers to HPV vaccine utilization in young female California *residents* (Oral)

AcademyHealth Annual Research Meeting 2010 Financial and nonfinancial barriers to HPV vaccine utilization in young female California *residents*(Poster)

#### **PROFESSIONAL MEMBERSHIPS**

AcademyHealth (national member and student chapter executive board member—secretary) American Public Health Association (national member) Health Care Transition Research Consortium Intercollegiate Athletics Committee (committee member 2013-2014)

# **CHAPTER 1: INTRODUCTION**

As advancements in diagnosis, treatment, surgical intervention, drug therapy, and management of illness[1, 2] have continued to progress over the past several decades, life-expectancy for many conditions have been extended from late adolescence to mid-40s.[3] [4] Sickle cell disease (SCD), previously considered an early-life death sentence, is one such condition.[3]

As children with sickle cell live longer, one consequence is that youth and young adults living with the disease face the experience of aging out of children's medical and health insurance programs. Researchers define a transition-age period between the ages of 14-17 as the critical period in which education regarding maintaining and obtaining health insurance and access to care as an adult should begin.[5-8] Early conversation is thought to reduce preventable gaps in insurance coverage for young adults ages 18-26 with child onset conditions, such as SCD.

Age-related cutoffs for eligibility to children's health programs have special implications for youth who are dependent on public programs and who have no other source of insurance. These cutoffs usually occur around the age of 18 to 21 years of age. Losing insurance may lead to diminished access to preventive and primary care services and reduced access to their usual providers, often experts on their chronic condition, and increase the risk of hospital and emergency department (ED) services. This may be observed for children who participate in public programs such as California Children's Services (CCS) that designate specific facilities and clinicians that are "paneled" to provide care based on their expertise and multidisciplinary care capacities. While a body of literature is rapidly growing on tracking the increase in young adult patients growing older with child onset conditions [1, 9-11], little research examines the impact of aging out of public program eligibility on hospital and emergency department use.

This dissertation examines hospitalization and emergency department use of individuals with sickle cell disease between the ages 14-26. This period spans the ages at which young adults supported by public programs or parent's employer-based dependent coverage may lose this insurance and the access to care it affords. If financial access to routine care is reduced, emergency department use may increase. Similarly, hospitals may have incentives to quickly treat and release putting these patients at greater risk for readmission or deterioration of their health.[12]

This study examines variations in hospital and emergency department use for several age groups of individuals with sickle cell disease. In addition to examining the association of use with age, it examines social disadvantage as defined by insurance status and insurance stability, distance to the nearest acute care hospital, and poverty status increase the likelihood of hospitalization, hospital readmission, longer lengths of hospital stay, and increased emergency department use.

The dissertation is organized as follows. Chapter two reviews the relevant literature that guided the development of the research questions. Chapter three presents a detailed conceptual model used to illustrate the relationships tested in this dissertation and descriptions of main concepts. Chapter four describes the research questions and hypotheses explored in this dissertation. Chapter five describes the data, sample selection methods, and the measures used in the analytic model building. Chapter six describes the statistical methods used to explore the impact of the primary predictors of interest on the outcomes of interests. Chapter seven and eight discuss the results and implications.

#### **CHAPTER 2: Background and Literature Review**

Approximately 100,000 people in the U.S. are inflicted with sickle cell disease. Every year in the U.S.1 out of every 500 non-Hispanic African American and 1 out of every 3,600 Latino are born with the disease.[13] Sickle cell trait, the benign condition, occurs in an estimated 1 out of 12 African American births.[13] While the prevalence of sickle cell is lower than more common chronic conditions such as child-onset diabetes or asthma, the frequency of hospitalization and emergency care use for a small group of individuals is high. In adulthood, sickle cell can require much more health-related services, including hospitalization, than otherwise healthy young adults would use. While increasing severity of the disease in adults compared to adolescents may contribute to the increased use, some of it may be the result of disruptions in medical care as young SCD patients transition out of age-restricted health insurance programs and have to shift from pediatric providers with substantial expertise in the disease into adult care settings with less expertise in caring for individuals with these chronic historically life-limiting diseases.[14]

#### 2.1 Defining Sickle Cell Disease as a Special Health Care Need

The Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), and the Maternal and Child Health Bureau (MCHB) defines individuals with special health care needs (SHCN) as "those who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by [individuals] generally."[15] SCHN conditions may impose physical limitations in performing activities of daily living and financial constraints as a result of high health care utilization. These conditions require medical management and intervention beyond the health care needs of a "healthy" individual. Conditions may be congenital, developmental, cognitive or mental/emotional in form or acquired through disease, trauma or environmental agent. [16] Treatment for individuals with SHCN conditions will likely include a medical specialist with additional training and knowledge [17, 18]

Sickle cell disease requires a high degree of medical management and hospital care. This inherited condition, predominantly affecting African Americans and Latinos, contorts the shape of healthy oxygen-carrying red blood cells restricting the flow of oxygen to parts of the body causing severe pain and possible organ damage.[13] Acute and multi-organ complications in childhood and adolescents resulting from the disease can be particularly financially burdensome for families and medical systems that care for these patients.

## 2.2 Specialized Health Insurance Programs (California Children's Services)

Funding for specialty care related to sickle cell or other SCHNs is provided by specially defined insurance programs to cover medical costs. California Children's Services (CCS) is one such specially defined program. In 2012, approximately 121,000 children older than one year of age were enrolled in CCS. Less than one percent of those beneficiaries were sickle cell children.[19] CCS provides diagnostic and treatment services, medical case management, physical, occupational, and medical therapy services to young persons with eligible medical conditions under 21 years of age. Eligibility ends on an individual's 21st birthday. The program is a collaboration between county health departments and the California Department of Health Care Services (DHCS). Examples of CCS eligible medical conditions include but are not limited

to chronic conditions such as congenital health disease, cystic fibrosis, spina bifida, cerebral palsy, hemophilia, cancer as well as sickle cell disease. In addition, the program covers traumatic injuries and infectious diseases.

The reimbursement by the CCS creates long term relationships with physicians, hospitals and other providers with high levels of experience and expertise treating individuals with these conditions. These programs may have income, age or other restrictions on who they can serve; thus, reimbursement through CCS opens access to these providers for CCS eligible children and young adults.

The California state Medicaid program, Medi-Cal, reimburses the cost of care for approximately 70 percent of CCS-eligible children. The Federal State Children's Health Insurance Program (SCHIP), in California called Healthy Families, also provides coverage for CCS-eligible low income children not eligible for Medi-Cal. Overall, 90 percent of CCS beneficiaries have Medi-Cal or Healthy Families[20]. A separate coverage mechanism called CCS-Only covers the cost of care for CCS-eligible children not enrolled in Medi-Cal or Healthy Families. Costs under CCS only are funded jointly by the state and counties, while costs under Healthy Families are funded by Federal Title XXI (State Children's Health Insurance Program).

#### 2.3 Link Insurance and Utilization/Access for youth with SHCN

The CCS program has established Special Care Centers for SCD patients and financially ensures access to effective medical treatments, such as prophylaxis and specialty drugs like hydroxyura that sustains health. There are multiple goals in health care delivery for youth with sickle cell disease, including extending life and functioning, an facilitating an individual's education attainment and social development despite missed days of school and loss of interaction with peers due to frequent engagement with the medical system.[21] Optimal management of the disease requires long term management with a primary care provider or having a medical home.[22] Previous studies have indicated difficulties in keeping a medical home in young adulthood for, trouble obtaining needed specialty care, primary care, receiving effective care coordination when needed, and maintaining adequate health insurance compared to children with SHCN.[23]

In California, SCD patients are now twice as likely to die in early adulthood (between ages 21 and 30) compared to when they were younger.[24] Two of the most common causes of illness and mortality, Acute Chest Syndrome (ACS) and splenic sequestration, is more common in children than in adolescents or adults. However, ACS episodes are 4 times more likely to be fatal in an adult than in a child. Therefore, it is unclear whether it is severity of illness alone or despite severity of illness, a particular age group that has more difficulties managing the illness. The growing difficulty in managing the disease in adulthood may be associated with higher utilization of inpatient and ED care.

Patient with sickle cell moving from childhood to adulthood may rely more heavily on emergency department use, because of relatively lower availability of adult specialist with experience treating sickle cell patients[25] Without easy access to primary care, emergency departments use may theoretically become an individual's usual source of care[22]. Moreover, hospitalizations may be become more frequent due to delays in primary care visits.

The focus of this dissertation is age associated utilization of health care by SCD patients. Increasing risk of hospitalization and ED use with age may be associated with the natural history of the disease and increasing severity, difficulties older patients have in managing their disease, and transitions in insurance coverage and health care providers. Recent studies suggest that age cut-off policies for service and insurance are associated with changes in access to care, which is often a concern for parents of youth with sickle cell and their pediatric team.[9, 26] An age cut-off policy is a key concern for the timing of moving from a children's insurance program into a comparable adult health insurance program. Loss of insurance because of an age-cut off point in early adult hood may coincide with increase severity of illness with progressive deterioration in quality of life and organ function [27-30].

Access problems may be associated with loss of insurance as individuals lose eligibility for Medicaid or coverage under their parent's insurance. Even those shifting to other insurance may be challenged to maintain effective relationships with health care expertise in their disease. Young adults entering the maze of the adult health insurance system with different eligibility requirements may be confusing and could lead to loss of insurance and access to the health care system. The potential gap in health insurance after aging out of children's health insurance programs may limit the ability to seek flexible ways to engage in the larger society and keep their health insurance.[26] Prior to the 2010 signing of the Patient Protection and Affordable Care Act (ACA), young adults with sickle cell would age out of parents' employer-based health insurance at age 18 except under certain conditions (i.e. full-time enrollment in higher education).

A 2006 study by Bloomquist surveyed young adult graduates of a state program for children with special healthcare needs and a specialty children's program over the age of 18. The survey asked about their current health insurance status and access to health care as an adult. Results from the survey were compared with data on typical young adults to determine potential disparities. Twenty-nine percent of graduates had no health insurance and only 11% had

employer-based insurance. Eighty percent reported having a usual source of care, but 42% used the emergency department compared with to only 25% of typical young adults who used the ED as their usual source of care[31].

Youth with sickle cell may find also that they have limited options for employment that is flexible with their frequent hospitalizations and emergency care visits. The disease can restrict participation in education as an avenue for sustained health care access and insurance. A primary consideration in choosing a university, for example, may be proximity to a comprehensive care center or education institution that offer comprehensive insurance coverage included in student tuition. These issues still remain for those with public insurance.

Moreover, minority young adults and those from low income families are known to experience insurance loss at higher rates during changes in their family and legal status than nonminorities and youth from middle-to-high income families. [14, 20] In general, youth and young adults of white ethnicity have higher rates of insurance coverage than African American or Latinos.[32] Furthermore, results of previous studies indicate that low income adolescents and young adults are more likely to report unmet medical needs than their counterparts in middle income or high income families due to lapses in insurance. Those who have experienced a lapse in insurance for greater than six months also report a greater need for medical care and prescription drugs even after restoring insurance.[33] For these reasons, it is important to monitor young adults with SCD as they age out of public insurance and become uninsured or gain other types of insurance programs.

The literature on the relationship between aging, insurance, hospital type and utilization patterns is still very limited. However, previous studies have shown an association between aging, hospital setting and increase using of hospital services among adults with similar child

onset conditions to SCD. Gurvitz et. al. examines predictors of admission as a function of age and insurance. Studies by Jan et al. and Okumura measure utilization difference between adolescents and adults treated in children's hospitals versus adult hospitals.

Gurvitz et al. evaluated hospitalization patterns during adolescence to mid adulthood for patients with congenital heart disease (CHD). The authors selected patients ages 12 to 44 from the 2000 to 2004 California hospital patient discharge databases. The objective was to predict the factors influencing admission source (e.g. the ED) for this patient population. Gurvitz et al. found that the patients admitted via the ED nearly doubles around the transition period to adulthood and positive predictors of admission via this source were public insurance, paying for care out-of-pocket, and age >17 years.[34]

Jan et al. performed a retrospective cohort study using two years of large multiinstitutional database. The author identified 1,476 patients with SCD and acute chest syndrome (ACS) ages 16 to 25 with associated 2,299 admissions discharged from 256 US hospitals. The author hypothesized a difference in outcomes between youth and young adults treated in children's hospitals (14% of the sample) versus general hospitals (86%). The outcomes examined included death rates, intubation rates and length of stay (LOS). Adjusting for age and four level indicator of severity of illness (from minor to extreme), general hospitals were associated with longer LOS compared with children's hospitals. [35] Out of the 14 deaths observed in the data, 13 deaths occurred in general hospitals. General hospitals were associated with higher intubation rates (predicted probability [PP], 48% [95% confidence interval (CI), 43%–52%]) and longer LOS (predicted mean LOS, 7.6 days [95% CI,7.2–7.9]) compared with children's hospitals (PP of intubation, 24% [95% CI, 5%–42%]; and predicted mean LOS, 6.8 days [95% CI, 5.6–5.8]). Although the authors saw significant difference between the two hospital types, they were unable test specific drivers of longer LOS. The authors hypothesized that the differences were likely due to including the role of staff expertise, hospital volume, and quality of ongoing SCD care.

Okumura et al. also examined inpatient length of stay (LOS) and related charges for adult survivors with child-onset chronic illness in the United States. Using the 2002 Nationwide Inpatient Sample (NIS) and multivariate analysis the authors examined differences for these two outcomes between young adults treated in children's hospitals versus adult hospitals for four child-onset chronic conditions including SCD. Adult patients with CHD and Cystic Fibrosis treated in children's hospital had a significantly longer length of stay and higher charges than those in the adult hospital. Sickle cell anemia and spina bifida patients had similar LOS in both settings, but higher charges were observed in the pediatric hospitals compared to adult hospitals. The author stratified by age in their analysis, and still saw longer LOS for CHD and CF, but not for SCD. Both Jan and Okumura recognized that outcomes may differ by hospital type. These studies do not include separate analyses from initial hospitalization versus readmissions. They do not analyze emergency department utilization. They do not track the same patients longitudinally across multiple years of data to examine patterns in utilization.[36] They do not differentiate between increased use due to increased severity as individuals with SCHNs age and challenges to obtaining care due to insurance and provider transitions.

This study addresses some of these limitations. It uses a multi-year date set in which individuals with SCD can be tracked over time. It expands the range of outcomes examined to include the count of hospitalizations and ED visits over time, and hospital readmission. While it cannot fully differentiate between increased use due to aging and increase severity of illness and transitions in insurance or treatment, it expands upon the prior work by using age, insurance changes, changes in hospitals across admissions or ED visits across visits, distance from hospital – to provide indications of whether insurance or provider changes may have independent effects on utilization. The limitations of these measures are discussed briefly when they are first presented, and further in the concluding chapter.

## **CHAPTER 3: OVERALL CONCEPTUAL MODEL**

Figure 1 below depicts the overall conceptual framework for this study. The model is adapted from the Andersen Behavioral Model of Health Services Use.[37] The original model describes how access to care is related to both contextual level and individual determinants. Community environment, institutional policies, and government laws and provisions encourage or restrict the use of health care services. Contextual level and individual level determinants are divided into predisposing, enabling, and need determinants. The term predisposing refers to demographic characteristics of a community or patient. Enabling refers to availability of services, policies/procedures, sources of support, and financial mechanisms that allow groups or individuals to obtain care. Need refers to health-related measures of the physical environment where someone lives. The model differentiates evaluated need from perceived need at the individual level. Perceived need refers to how symptoms and signs of illness are filtered through the patient's perception. Evaluated need represents professional assessment.

The conceptual model presented in Figure 1 includes both measurable items and those not measurable with data used in this study. Those items which can be measured in this study are in bold in the Figure and are described in the text.

#### Contextual Individual **Health Behaviors** Utilization of Personal Health **Predisposing** Predisposing Services Family/Patient Income (ACS Proxy) Gender Number of outpatient and preventative Family/Patient Poverty Status (ACS Age care visits Proxy) **Race/ethnicity** Family/Patient Education (ACS Proxy) **Number of Index Hospital Admissions** Family/Patient Employment Number of 30 day Readmissions Family/Patient Marital Status Enabling Length of Stay Family/Patient Social Support Age eligibility\*Insurance Status Place of Residence **Number of Emergency Department** Visits **Distance from Home to Nearest** Acute Care Hospital Enabling Self-efficacy **Hospital availability Transportation Support Hospital Type** Health Literacy Children's vs. General **Teaching Status** Need Hospital Age-Out or **Transition Policies and** Comorbidities Practices Natural history of illness Need **Perceived Health Status** Medically Underserved Area Other community characteristics influencing health, e.g.

# Figure 1: Adaptive Health Utilization Model by Contextual and Individual Level

- Environmental quality
- Crime Prevalence
- Food Quality

# 3.1 Measurable Contextual Level Variables:

Pervious research supports the notion that individual health practices are influenced by the characteristics of the places where people reside. Characteristics of communities, such as the availability and accessibility of health services, institutional policies, prevailing attitudes toward health, and environmental conditions, may influence general health and the use of heath care resources. [11] Income, poverty level and educational attainment within a community speaks to predisposed determinants of access to care. Higher income, lower poverty communities where a greater number of college graduates reside typically suggests more available health and health care related resources. [38] Likewise, **place of residence** speaks to not only the above concepts but also includes racial/ethnic composition. Studies show that living in areas with larger proportion of minorities may be either a positive protective factor or negative influences for African American and Latinos. Living in areas with others with shared backgrounds, language and culture can facilitate greater dissemination of health education, especially if these areas are populated with minority health care providers.[39] On the other hand, these areas are more likely to have higher crime prevalence and lower healthy lifestyle resources.[39] Racial composition is one component of differences across geography. Availability of medical resources, crime rates, food-quality and employment are also components.

**Hospital type** is an enabling factor which refers to adult versus children's hospital. As stated in the introduction of this dissertation, utilization outcomes may differ between settings due to the availability of pediatric disease specialists in children's hospitals compared to adult

hospitals.[18] For example, longer length of stay has been observed in pediatric hospitals versus adult or general hospitals for patients with sickle cell disease.[35]

## 3.2 Measurable Individual Level Variables:

Age is both a predisposing and enabling indicator for increasing severity of illness and medical complications and insurance eligibility. Research shows age-related declines in access to care among Latino and African American young adults and those of low-income.[40] While young adults between ages 18 and 30 are expected to take an increasing role in navigating the health insurance system, during this vulnerable age period they often lack the knowledge to navigate effectively. Moreover, adolescents and young adults with SCD are more likely to experience mood disorders such as depression and anxiety (related to frequent pain episodes) compared to their typical peers [41]. Psychosocial issues further complicating their ability to sustain employment and health insurance.

Level of care utilization may be differentiated by **Race/Ethnicity**. Although sickle cell disease is more common among African American and Latinos, race/ethnicity is still important to distinguish as an individual level factor. African Americans and Latinos are known to have higher utilization rates related to being less likely to engage in self-care skills, such as medication adherence and self-testing, and lower access to primary care compared to other racial/ethnic groups.[42]

Utilization outcomes may differ by **gender**. Evidence indicates gender differences in severity of illness. Studies show that males have higher painful crises per year, chronic obstructive pulmonary disease, leg ulcers, stroke, chronic renal disease, pulmonary hypertension than females in their same age cohort. Furthermore, studies cite lower male ratio of patients

without any painful crisis, lower mean ages of male SCDs patients with mortality, and longer overall survival of females with sickle cell [43]. For females, changes in disease during pregnancy may occur. Sickle cell crisis during pregnancy may still occur as well as infections, iron deficient anemia and related heart enlargement or failure, and organ complications will increase the need for more emergency or inpatient care services [44].

It is necessary to account for **insurance status** as it indicates patient and family resources and access to care. Patients with Medicaid coverage and who are uninsured have been found to utilize ED care more frequently, and it was hypothesized that this was due to a lower likelihood of follow-up care with a primary care physician compared to privately-insured patients.[45] Medicaid children and youth have more gaps in care during the year compared to children with private insurance.[46]

**Distance from home to nearest hospital** as a measure of travel burden is a key concept in assessing access to care[47]. Added distance of even one mile to the nearest hospital may result in a significant decrease in ease of access to health care increasing the risk of adverse (e.g. delayed emergency room care for sickle cell related pain episodes).[48] In 2001, the average travel distance to receive care in the U.S. was 10.2 road miles (16.4 kilometers) equating to 22 minutes of travel to the nearest care center. In this dissertation, distance to the nearest hospital will be used as a proxy for access to hospital services and travel burden.

**Comorbid** conditions have been found to be correlated with repeat ED visits and longer LOS.[49, 50] Patients with unscheduled readmissions are more likely to have a higher comorbidity burden.[50]

#### 3.3. Measureable Utilization of Personal Health Services

**Hospital admissions (index hospitalizations)** dependent variable is the first outcome of interest in this dissertation. Increasing admission rates by age group may be associated with exacerbated health problems as at-risk individuals grow older (e.g. accumulated health conditions with age), financial challenges to obtaining primary and preventive services as individuals age out of Medicaid or their parent's insurance, and changes in usual source of care from pediatric to adult providers. In this study, we differentiate between hospitalizations that are new admissions and those that may be readmissions following the original index admission.

**Readmissions within 30 days** following a patient's previous admission may signal lower quality care or more health problem during young adulthood.[51] Readmission are expensive and financial pressure to discharge patients may increase readmission without extensive discharge planning for high-risk sickle cell patients.[52] The National Association of Children's Hospitals and Related Institutions (NACHRI) has established a 30-day readmission measure for Sickle Cell Disease (SCD) as a new benchmark for quality care in children.[53] Although the validity of the readmission measure is controversial because of inconsistent definitions across studies and improper case-mix adjustments, many organizations still consider it to be an important outcome variable.[46, 52, 54] For this reason it is included as a measure in this dissertation.

**Emergency department visits** can also be used as a measure of poor quality of care or inadequate access to primary care services due to financial limitations. Insurance type is a determinant of use of the emergency care department related to access to other facilities that may

serve as a usual source of care. While some young adults may increase utilization because of severity of illness, others will use because of lack of access to primary care providers. [55] In addition, it is well documented that lapses in insurance may increase emergency room utilization.[56, 57]

LOS is used as an indicator for intensity of care needed to treat a certain condition, and is correlated with the costs associated with treatment. It can also reflect quality of care, patient severity due to the progression of the disease or adequacy of primary and preventive services, and availability of community based services post-discharge. For example, LOS would be extended for complications caused by delays in care or poor quality of care or inability to discharge a patient to an appropriate environment[58, 59].

In this chapter, I have described the overall conceptual model illustrating the relationships under examination in this dissertation and the independent and dependent variables that are available for analysis, including justification for including each measure. Analytic models by outcomes being studied is presented in chapter 6 and only included measurable variables.
#### **CHAPTER 4: Research Questions and Hypotheses**

The conceptual model presented in the previous chapter describes relationships between observable measures of health care utilization, age, insurance, and socio-economic factors. Two research questions and corresponding hypotheses were development and analyzed based off the understanding of associations between factors in Figure 1. The research questions and hypotheses are presented below:

4.1 Age-Related Research Questions and Related Hypotheses.

**Research Question A.** Does utilization of inpatient and emergency department services differ across age groups (14-17, 18-20, and 21-26) among patients with sickle cell?

**Hypothesis A1.** Ages 21-26 (age cutoff for CCS coverage) or 18-20 will be associated with greater number of index hospitalizations when compared to patients with sickle cell ages 14-17.

**Hypothesis A2.** Ages 21-26 (age cutoff for CCS coverage) or 18-20 will be associated with higher odds of at least one readmission when compared to patients with sickle cell ages 14-17.

**Hypothesis A3.** Ages 21-26 (age cutoff for CCS coverage) or 18-20 will be associated with longer length of stay per hospitalization when compared to patients with sickle cell ages 14-17.

**Hypothesis A4.** Ages 21-26 (age cutoff for CCS coverage) or 18-20 will be associated with greater number of ED visits when compared to patients with sickle cell ages 14-17.

**Rationale for the Hypotheses:** As discussed in Chapter 3, more frequent use of hospitals and EDs, greater likelihood of readmission, and longer lengths of stay may be associated with age because of the natural history of the illness over time, and transitions in health care providers to physicians and hospitals with less familiarity with the patient or disease due to changes in insurance and transition from pediatric to adult providers. The breaks in the three age categories, at 18 and 21, have been chosen to coincide with frequent transition points for insurance.

4.2 Socio-Economic Status Research Question and Related Hypotheses

**Research Question B:** Does utilization of inpatient and emergency department services differ for socially disadvantaged patients with sickle cell defined by lack of insurance, living in higher average poverty areas, and greater travel burden (distance from home to nearest hospital)?

**Hypothesis B1.** Being uninsured, longer distance to the nearest hospital, higher poverty will be associated with greater number of index hospitalizations compared to those insured, living closer to an acute care hospital, and lower poverty.

**Hypothesis B2.** Patients with sickle cell who are uninsured and living in higher poverty areas will have higher odds of at least one readmission than those insured and lower poverty. Patients living further from the hospital will have lower odds of readmission.

**Hypothesis B3.** Living further from a hospital and higher poverty will be associated with longer length of stay. Being uninsured will be associated with shorter length of stay.

**Hypothesis B4.** Being uninsured and higher poverty will be associated with greater number of ED visits compared to those insured, and lower poverty. Those living further from a hospital will have lower numbers of ED visits.

**Rationale for Hypotheses:** Being uninsured may reduce use of routine preventive and maintenance care and follow-up care post-hospitalization, and increase the risk of hospitalization, ED use, and readmission. Being uninsured may be associated with lower length of stay because of the incentive on hospitals to limit unreimbursed care. Higher poverty in the area of residence will be associated with more admissions and ED visits, and readmissions because high poverty areas are less likely to have primary care and follow-up services needed to prevent admission, ED use and readmission. It may also proxy for a patient's and patient's family's financial and other resources to purchase or effectively use outpatient services and manage SCD. Higher poverty may be associated with longer length of stay because it proxies for poorer health status due to lack of access to care in the community or effective self-management, and because hospitals may find it more difficult to assure the availability of post-discharge services that will allow discharge from the hospital.

Longer distance from home the nearest hospital will be associated with more admissions because it may be associated with less access to specialists such as pediatric hematologists. Distance will be associated with lower risk of readmission because hospitals may keep patients who live further from the hospital, particularly those in rural areas, to assure that they are stable before being returned home or to environments with fewer services. For this reason, length of stay may be longer for those who live further from a hospital.

How these hypotheses will be tested is discussed in Chapters 5 and 6.

### **CHAPTER 5: DATA AND MEASUREMENT**

## 5.1 Data Sources

### 5.1. California Office of Statewide Health Planning & Development (OSHPD) data sets

The Office of Statewide Health Planning & Development (OSHPD) non-public patient discharge database (PDD) and non-public emergency department database (EDD) for hospitalizations and ED encounters not resulting in admission at the treating hospital were used in this dissertation. The PDD and EDD include all inpatient stays and ED visits at all non-Federal and non-prison general acute care hospitals in California and allow for the analysis of rare and complex illnesses. Hospitals submit discharge abstracts or emergency department encounter reports to OSHPD for each admission or encounter to a licensed general acute care hospital in the state of California. Each facility reports their discharge data via the Medical Information Reporting for California System (MIRCal). The PDD and EDD databases currently use the International Classification of Disease, Ninth Revision, Clinical Modification (ICD-9-CM) for reporting primary and secondary diagnosis and procedure codes. ICD-9-CM codes are assigned to each individual hospital discharge by California hospitals in which there are open fields for up to 24 primary and secondary diagnoses and 20 procedures. Non-public datasets include a patient identifier called the record linkage number (rln); a unique 9-digit alphanumeric value created by encrypting the patient's Social Security Number (SSN). [60, 61] Hospitals are not required to collect SSN, but if SSN is collected, it must be reported. Six years of PDD and EDD data covering discharges and encounters from January 1, 2006 to December 31, 2011, were requested for this study. OSHPD does not include ED encounter data for ED visits that result in hospitalization. In this analysis, an ED record was constructed for a patient for each

hospitalization with the ED as the source of admission in order to evaluate all SCD presentations to the ED during the six years.

#### 5.2. American Community Survey

The American Community Survey (ACS) 2007-2011 was used to obtain proxy socioeconomic information on patients. The ACS is an ongoing survey that provides annual demographic data on individuals in communities. The ACS collects information on age, sex, race, education, family and relationships, income and benefits, health insurance, and disabilities. Rolling five year cumulative estimates have been created by the Census Bureau in place of the Census Long Form, which was not collected in the last decennial census. For this study, data elements from the ACS on average household income and education were linked to OSHPD data by zip code of patient residence to obtain proxy socio-economic (SES) information on the sickle cell patients.

#### 5.3 Sample Selection

Each year of PDD and EDD data was examined using statistical software SAS version 9.2 Enterprise. A sample of adolescent and young adult sickle cell patients was selected using the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes in a five step process. Figure 2 displays the inclusion and exclusion criteria in selection of the sample and the final sample sizes. Both primary and secondary diagnoses were examined to insure identification of all patients with sickle cell disease. Step one was to select all observations with a primary ICD-9-CM diagnosis of sickle cell disease (282.41, 282.42, 282.6, 282.60, 282.61, 282.62, 282.63, 282.64, 282.68, 282.69). The benign condition of sickle cell trait, inherited sickle cell gene but never display symptoms, was excluded from this study because hospitalizations would be infrequent and likely unrelated to sickle cell. A description of each ICD-9-CM code is provided in Table 1. Step two was to select all observations with at least one secondary diagnosis of sickle cell. Step three was to exclude any observation with missing patient (rln) identifiers because individual patients could not be distinguished. Step four was selection of any additional observation reported with the same rln as those extracted from step 1 and 2, but was not coded with a primary or secondary diagnosis of sickle cell to capture complete utilization of patients with sickle cell. In step five, all observations obtained in step one and two were cross-checked with their respective procedure codes to determine if these individuals received treatment commonly administered to sickle cell patients (Table 2). Table 2 shows that common procedures were related to diagnostic or treatment of sickle cell crisis or complications or child birth

ICD-9-CM	Label
282.41	Sickle-cell thalassemia without crisis
282.42	Sickle-cell thalassemia with crisis
282.6	Sickle-cell disease
282.60	Sickle-cell disease, unspecified
282.61	Hb-SS disease without crisis
282.62	Hb-SS disease with crisis
282.63	Sickle-cell/HB-C Disease without crisis
282.64	Sickle-cell/HB-C Disease with crisis
282.68	Other sickle-cell Disease without crisis
282.69	Other sickle-cell Disease without crisis

Table 1: ICD-9-CM List and Description

	Inpatient (n=13,3	335)
	n	Percent
No Procedure codes	6,306	47
Transfusion of packed cells (99.04)	3,501	26
Venous catheterization, not elsewhere classified (38.93)	694	5
Other manually assisted delivery (73.59)	188	1.41
Low cervical cesarean section (74.1)	158	1.18
Laparoscopic cholecystectomy (51.23)	118	0.88
Diagnostic ultrasound of heart (88.72)	102	0.76
	Emergency Department	(n=27,001)
	n	Percent
No Procedure codes	11,701	44
Transfusion of packed cells (99.04)	2,793	10
Emergency Services (99283, 99284 and 99282)	3,517	12.5
Routine Venipuncture (36415)	718	3
Venous catheterization, not elsewhere classified (38.93)	597	2.2
Therapeutic/ prophylaxis / diagnostic injection		
subcutaneous and intramuscular (96372, 90774, and	014	2.5
90772) Badiologic Examination Chest 2 views frontal and	914	3.5
lateral (71020)	287	1.1
Complete Blood Count (CBC) (85025)	231	1

Lastly, primary diagnosis codes were examined for all observations obtained in step two to understand additional reasons patients visited the emergency room or were admitted aside from sickle cell. Particularly within the EDD data, this step allowed for a better understanding of whether patients were seeking primary care versus actual emergency care related or unrelated to their sickle cell. In addition, primary procedure codes were reviewed for all patients selected in step one to check for accuracies in coding. Because this study is an analysis of whole history of hospitalizations of high-risk events related to sickle cell, pregnancy-related hospitalizations among this sample population (5%) were included in this analysis.

Patients residing out of state (0.01% of sickle cell related hospitalizations and visits in PDD and EDD) were excluded because these individuals would not be subject to California insurance eligibility thresholds nor would they experience the same insurance product services as in-state residents. Moreover, post-discharge follow-up data are unreliable for these patients.

# Figure 2: Flow Chart of Inclusion/Exclusion Sample Selection Process



#### 5.4 Dependent Variables

Four dependent variables were developed or extracted from the OSHPD data: 1) count of index hospitalizations 2) experienced at least one 30 day readmission 3) length of stay and 4) count of ED visits. A full description of each is provided below:

**Count of index hospitalizations:** The count of index hospitalizations variable was derived by using two existing items in OSPHD, admission date and discharge date. For each patient in the data identified by the rln, hospitalizations were sorted by admission date. Hospitalizations were again sorted by individual patient and the number of days between the discharge date of the previous admission and the current admission date was calculated for each observation. If the number of days was greater than or equal to 30 days the observations were labeled an as index hospitalization. Each patient's first observation in the six years of data was labeled as an index hospitalization. The count of index hospitalizations was then calculated. The unit of analysis for the count of index admissions was the individual patient as identified by the rln.

Thirty day Readmission: The thirty-day readmission measure for sickle cell crisis is used by the National Association of Children's Hospitals and Related Institutions (NACHRI) to monitor hospital quality.[18] Observations within 30 days after a previous discharge were labeled a readmission. A binary variable was created to indicate whether at least one readmission occurred following the index hospitalizations. In the analysis of readmissions, the unit of analysis was each index hospitalization. Length of stay. LOS was a preexisting variable in the inpatient dataset. OSHPD defines LOS as total hospital days per visit. Lengths of stay of zero days are possible if discharge occurs on the same calendar day as the admission. A zero day length of stay was rare, accounting for 2.3% of the PDD full sample. Discharges in the same day as admissions were frequently associated with patients leaving against medical advice (28.9%) or transferring to another hospital/death (approximately 8%). Length of stay was analyzed for all admissions, whether index admissions or readmissions.

**Count of ED visits.** Visits that resulted in discharge from the ED or resulted in admission to the hospital were both counted. For each individual in the discharge data set, a record was added to the ED data set for each admission that occurred through the ED. For each individual, the count of ED visits in the augmented data set was constructed as the total number of visits.

## 5.5 Independent Variables: Primary Predictor of Interest

Four primary predictors of interests were selected or created from existing items in the PDD and EDD datasets. They included age, insurance status, insurance switching, and distance from home to hospital.

Age Group. For the analysis of thirty-day readmission and LOS, age at admission was categorized into three groups (14-17 vs. 18-20 and 21-26). For the analyses of counts of hospitalizations and ED visits, defining an age variable was complicated by two circumstances. First, for many individuals, there were multiple hospitalizations and they could have occur at any point in the 2006-2011 timeframe. Second, the data sample was constrained to

hospitalizations for individuals who were between the ages of 14 and 26 at the time of hospitalizations. Hospitalizations in 2006-2011 for individuals who became 14 after January 1, 2006 or became 27 before December 31, 2011 would not be counted. To accommodate for these limitations two variables were included in regressions. The first was the age at which a hospitalization could have been observed, which would be the individual's age at January 1, 2006, or age 14, whichever was older. The second variable included was the number of days in the 2006-2011 period in which a hospitalization could have been observed in the data. The total number of days in the period in which the individual was between the ages of 14 and 26 was divided by the maximum, 2191 days, to create the **proportion of days observed**.

**Insurance status.** Insurance status is constructed from the expected source of payment as reported on the inpatient discharge abstract or the ED encounter form. Detailed mapping of OSHPD categories to the four analytic categories are presented in Tables 3 and 4. OSHPD reports 10 categories of expected source of payment on the inpatient discharge abstract and 21 on the ED encounter form. These were combined into four categories: Medicare, Medi-Cal or other government, Private Insurance, and Uninsured or government or private indigent care programs. The original categories Indigent care and self-payer were combined and the original category other with sample size 20 hospitalizations was combined resulting in four categories. All Medicare categories from the ED encounter form were combined. Uninsured, county indigence and other indigence categories were combined in the Uninsured category.

For the thirty day readmission analysis, insurance status reported on index hospitalizations was used. For the length of stay analysis, insurance status for the specific admission was used. For the analysis of counts of index hospitalizations and ED visits, insurance status was taken from each individual's last hospitalization. Since multiple observations were used to construct the counts, and insurance was different for some individuals across multiple observations, a choice was made about which insurance status to use.

Previous studies have found some degree of miscoding of Medicaid, self-pay and private insurance. For example, hospitalizations are coded as Medicaid even if the patients gained Medicaid coverage as a result of the hospitalization.[62] In the analysis, we use the insurance status as reported, and discuss this issue in Chapter 8 as a potential limitation of the study.

**Insurance Switching.** Over the study period (2006-2012), some patients with multiple hospitalizations or ED visits had different expected sources of payment across their visits. Analysis of patterns of insurance change showed that most patients' expected source of payment changed from Medicaid to Private (3%), followed by Medicaid to Medicare (1%), and Medicaid to Uninsured or other county indigent programs (2%). The insurance changes are important because they may be associated with changes in providers or provider networks, which lead to lack of continuity of care. However, change in insurance was conceptualized as a binary variable rather than type of change due to low frequencies. For patients with only one observed hospitalization or ED visit and for first hospitalization and ED visits, this variable is set to no switching. For the analysis of counts of index hospitalizations or ED visits any switching was indicated. For the analysis of thirty day readmission and length of stay, switching was indicated compared to the prior admission or visit.

**Distance from home to nearest hospital.** For the thirty-day readmission and length of stay analysis, distance from home to nearest hospital was a continuous variable calculated in miles by using distance between zip codes centroids for zip code of patient residence and zip

code of all acute care hospitals in California. In the analysis of counts of index hospitalizations and ED visits analysis, the distance measure was the distance to the closest hospital from the individual's last admission. Since multiple observations were used to construct the counts, and insurance was different for some individuals across multiple observations, a choice was made about which insurance status to use. For these two count models, distance from home to nearest hospital was divided by 100 to rescale the variable to a reasonable range. Distance from home to treating hospital was not used in analysis as it was considered endogenous.

**Percent poverty status.** Poverty status, the final primary predictor of interest, was pulled from the ACS and merged by zip code to both the PDD and EDD datasets. Poverty was categorized into three levels (0-24%, 25-49% and 50% and above). In the ACS, poverty status was determined for all people except institutionalized individuals (i.e., people in college dormitories, people in military group quarters, and unrelated individuals under 15 years old were excluded from the numerator and denominator when calculating poverty rates). Poverty status was defined as percent of the population in the zip code considered below poverty (<200% federal poverty level (FPL)) within the last 12 months of the survey. If a family's or unrelated individual's total income is less than the dollar value of the appropriate threshold, then that family and every individual in it were considered to be in poverty. The Census Bureau uses a set of dollar value thresholds that vary by family size and composition and does not vary geographically. Thresholds are updated annually to adjust for cost of living inflation using the Consumer Price Index (CPI).<sup>1</sup>

<sup>&</sup>lt;sup>1</sup> How is poverty calculated in the ACS. Accessed on April 20, 2014. Retrieved from http://www.census.gov/hhes/www/poverty/poverty/cal-in-acs.pdf

In addition to poverty status, average household income, and percentage of the population that completed college within the zip code were also extracted from the ACS but not included in analysis, as they were collinear with the poverty measure.

OSHPD Variable	Description	Categories	Variable in dissertation
Admission date	The date a patient was admitted to the hospital for inpatient care. The date a patient was discharged from the	N/A	Used to create dependent variables
Discharge date	hospital. Age of the patient (in days) at admission. This data element is based on the reported admission date and patient's date	N/A	Used to create dependent variables
Age in Years(at	of birth		Age Group (14-17, 18-20, 21-26) and Age Group on January 1, 2006
Admission) Expected source of payment	The type of entity or organization expected to pay the greatest share of the patient's bill.	N/A 01 = Medicare 02 = Medi-Cal 03 = Private Coverage 04 = Workers' Compensation 05 = County Indigent Programs 06 = Other Government 07 = Other Indigent 08 = Self Pay 09 = Other Payer	<ul> <li>(14-17, 18-20, 21-26)</li> <li><i>Insurance status</i> categorized into four levels: Medicare, Medicaid/other government, private, uninsured.</li> <li>1=Medicare (original variable=01)</li> <li>2=Medicaid/other government (original variable=02 and 04</li> <li>3=Private, (original variable=03)</li> <li>4=Uninsured/government or private indigent care programs</li> <li>(Original variable modified by combining categories 04, 05, 07, 08 and 09)</li> </ul>

## Table 3: List of Original PDD OSHPD Variables Selected for Dissertation Analysis.

Expected source of	The type of entity or	01 = Medicare	Insurance Switching-binary variable (yes or no)
payment	organization expected to	02 = Medi-Cal	For index and ED analysis
	pay the greatest share of	03 = Private	no=one observed hospitalization or ED visit
	the patient's bill.	Coverage	yes=change over the six years
		04 = Workers'	For the readmission and LOS analysis
		Compensation	no=one observed hospitalization or ED visit
		05 = County Indigent	yes=change in the four-level insurance status since the prior
		Programs	admission or visit
		06 = Other	
		Government	
		07 = Other Indigent	
		08 = Self Pay	
		09 = Other Payer	
		00 = Invalid/ Blank	
Percent Poverty	percent of the	0-100%	Poverty status- is a categorical variable with 3 levels 0-24%, 25-49%
Status	population in the zip		and 50% and above)
	code considered below		
	poverty within the last		
	12 months of the ACS		

Patient county	The patient's county of residence. OSHPD assigns the county of residence based on the patient's reported ZIP Code. Because ZIP Codes can cross county boundaries, OSHPD assigns the county with the greatest population in the respective ZIP Code.	All counties in California	<ul> <li>place of residencecounties combined into the three regions of California: north, south and central with exception of the most populated county, Los Angeles. The variable was four levels.</li> <li>1 = Lost Angles</li> <li>2 = South (Imperial, Kern, Orange, Riverside, San Bernardino, San Diego, Saint Luis Obispo, Ventura, Santa Barbara)</li> <li>3 = Central (Fresno, Kings, Madera, Merced, Mariposa, Monterey, Stanislaus, Tulare, Tuolumne, San Benito)</li> <li>4 = North (all other counties in California)</li> </ul>
OSHPD hospital identification number	6 digit unique identifier for each hospital	Numerical value	<ul> <li>Hospital Type: A binary variable identifying the treating hospital as a children's hospital or general/adult hospital</li> <li>Hospital Switching- binary variable (yes or no)</li> <li>For index and ED analysis</li> <li>no=one observed hospitalization or ED visit</li> <li>yes=change over the six years</li> <li>For the readmission and LOS analysis</li> <li>no=one observed hospitalization or ED visit</li> <li>yes=change in the four-level insurance status since the prior admission or visit</li> </ul>

Normalized Ethnicity/Race Group	The normalized race group for a patient based on a combination (merged) of their reported race and ethnicity.	0 = Unknown / Invalid / Blank 1 = White 2 = Black 3 = Hispanic 4 = Asian / Pacific Islander 5 = Native American / Eskimo / Aleut 6 = Other	Race/ethnicitythree level variable of 1= African American, 2=Latino and 3=Other. In the original variable, values 1, 4, and 5 only appeared for mixed individuals or in cases of race/ethnicity miscoding in the study sample.
Source of admission-Route	The route by which the patient was admitted.	<ol> <li>1 = The admitting hospital's Emergency Room (ER)</li> <li>2 = No ER or another facility's ER</li> <li>0 = Invalid / Blank</li> </ol>	<b>Route of admission</b> a binary variable of 1= admitted via the ED and (2) admitted from another facilities ED or admitted from other source other than ED. Original variable modified by merging category 0 into 2.

Note: Year of admission is marker for the year the data was collected. Co-morbidities were derived using HCUP comorbidity software version 3.7

OSHPD Variable	Description	Categories	Variable in dissertation
Service date Age in Days (at time of	The service date is the start of care provided to the patient in the emergency department or ambulatory surgery, whichever occurred first. Age of the patient (in days) at time of service. This data element is based on the reported admission date and natient's date of birth	N/A	Used to create dependent variables
service)		N/A	Age Group and Age Group on January 1, 2006

## Table 4: List of Original EDD OSHPD Variables Selected for Dissertation Analysis.

Expected Source of Payment	The type of entity or organization expected to pay the greatest share of the patient's bill.	09 = Self Pay 11 = Other Non-federal Programs 12 = Preferred Provider Organization (PPO) 13 = Point of Service (POS) 14 = Exclusive Provider Organization (EPO) 16 = Health Maintenance Organization (HMO) Medicare Risk AM= Automobile Medical BL = Blue Cross/Blue Shield CH = CHAMPUS (TRICARE) CI = Commercial Insurance Company DS = Disability HM= Health Maintenance Organization MA= Medicare Part A MB= Medicare Part B MC= Medicaid (Medi-Cal) OF = Other Federal Program TV = Title V VA = Veterans Affairs Plan WC= Workers'	<i>insurance status</i> categorized into four levels: Medicare, Medicaid/other government, private, uninsured. 1 =Medicare (Original variable modified by combining categories MA, MB, and 16) 2=Medicaid/other government (Categories MC, 11, OF, TV, VA) 3=Private (12, 13, 14, BL, CH, CI, DS, HM, WC, and AM ) 4=Uninsured/government or private indigent care programs . (all other categories and 00 and 09 were combined )
		TV = Title V VA = Veterans Affairs Plan WC= Workers' Compensation Health Claim 00 = Other	
		99 = Invalid/Unknown	

Expected Source of Payment	The type of entity or organization expected to pay the greatest share of the patient's bill.	09 = Self Pay 11 = Other Non-federal Programs 12 = Preferred Provider Organization (PPO) 13 = Point of Service (POS) 14 = Exclusive Provider Organization (EPO) 16 = Health Maintenance Organization (HMO) Medicare Risk AM= Automobile Medical BL = Blue Cross/Blue Shield CH = CHAMPUS (TRICARE) CI = Commercial Insurance Company DS = Disability HM= Health Maintenance Organization MA= Medicare Part A MB= Medicare Part B MC= Medicaid (Medi-Cal) OF = Other Federal Program TV = Title V VA = Veterans Affairs Plan WC= Workers' Compensation Health Claim 00 = Other	For index and ED analysis no=one observed hospitalization or ED visit yes=change over the six years For the readmission and LOS analysis no=one observed hospitalization or ED visit yes=change in the four-level insurance status since the prior admission or visit
		99 = Invalid/Unknown	

Patient county	The patient's county of residence. OSHPD assigns the county of residence based on the patient's reported ZIP Code. Because ZIP Codes can cross county boundaries, OSHPD assigns the county with the greatest population in the respective ZIP Code.	All counties in California	<ul> <li>place of residencecounties combined into the three regions of California: north, south and central with exception of the most populated county, Los Angeles. The variable was four levels.</li> <li>1 = Lost Angles</li> <li>2 = South (Imperial, Kern, Orange, Riverside, San Bernardino, San Diego, Saint Luis Obispo, Ventura, Santa Barbara)</li> <li>3 = Central (Fresno,Kings, Madera, Merced, Mariposa, Monterey, Stanislaus, Tulare, Tuolumne, San Benito)</li> <li>4 = North (all other counties in California)</li> </ul>
OSHPD hospital identification number	6 digit unique identifier for each hospital	Numerical value	Hospital Type: A binary variable identifying the treating hospital as a children's hospital or general/adult hospital Hospital Switching- binary variable (yes or no) For index and ED analysis no=one observed hospitalization or ED visit yes=change over the six years For the readmission and LOS analysis no=one observed hospitalization or ED visit yes=change in the four-level insurance status since the prior admission or visit

Gender	Gender of the patient for the current admission. "Other" includes sex changes, undetermined sex, and live births with congenital abnormalities that obscure sex identification. "Unknown" indicates that the patient's gender was not available from the medical record. Reported invalid values for sex were defaulted to missing "."	. = Invalid 1 = Male 2 = Female 3 = Other 4 = Unknown	Male=binary variable 1=Male and 0=Female For this sample, only 1 and 2 categories were displayed in the original variable.
Race Group – Normalized	The normalized race group for a patient based on a combination (merged) of their reported race and ethnicity. If a patient's ethnicity is "Hispanic" then the race group is coded as "3 – Hispanic". For example, White/Hispanic is assigned to code "3 – Hispanic".	0 = Unknown / Invalid / Blank 1 = White 2 = Black 3 = Hispanic 4 = Asian / Pacific Islander 5 = Native American / Eskimo / Aleut 6 = Other	<b>Race/ethnicity-</b> -three level variable of 1= African American, 2=Latino and 3=Other. In the original variable, values 1, 4, and 5 only appeared for mixed individuals or in cases of race/ethnicity miscoding in the study sample.

Note: Year of admission is marker for the year the data was collected. Co-morbidities were derived using HCUP comorbidity software version 3.7 5.6 Independent Variables: Control Covariates

**Primary diagnosis of SCD.** This study captured all hospitalizations of patients identified with sickle cell disease. Primary diagnosis was included to control for potential bias related to including non-sickle cell coded hospitalizations.

**Place of residence.** Place of residence was included to control for regional variations in care. It was coded into five categorical variables reflecting geographic regions in California: Los Angeles County (reference), Northern California, Central California, and Southern California.

**Hospital Type.** A binary variable identifying the treating hospital as a children's hospital or general/adult hospital was constructed to control for differences in provider expertise. OSHPD hospital identification number (a 6 digit unique identifier for each hospital) reported on each record was used. The list of OSHPD hospital id codes was cross-checked with their corresponding hospital names as reported on the OSHPD web site. This list was cross-referenced to a list of California Children's Hospitals provided by The National Association of Children's Hospitals and Related Institutions (NACHRI).<sup>2</sup>

**Hospital Switching.** A binary measure of hospital switching was constructed to control for changes in care and variations by treating facility. For patients with only one observed hospitalization or ED visit or for the first hospitalization or ED visit, this variable was set to no switching. For the analysis of counts of index hospitalizations or ED visits any acute care facility change over the six years resulted in this variable being coded yes. For the analysis of thirty-day readmission and length of stay, the variable was coded yes if individuals received treatment from a different hospital since the prior hospitalization or visit.

<sup>&</sup>lt;sup>2</sup> http://www.childrenshospitals.net//AM/Template.cfm?Section=Home3

**Primary diagnosis of sickle cell.** A binary indicator for hospitalizations with a primary diagnosis was included in the thirty-day readmission and LOS analysis to control for potential bias related to including non-sickle cell coded hospitalizations.

**Gender.** Gender of the patients was indicated in the models with female as the reference group.

Race/ethnicity. OSHPD data includes self-reported patient race/ethnicity. The original variable was normalized to include grouped race and ethnicity categories (e.g. non-Hispanic African American). Race/ethnicity is categorized into non-Hispanic African American (reference), Hispanic, and other. Other included mix-race individuals and those already coded as "other" in dataset. Individuals with different race/ethnicity reported across hospitalizations or visits were assigned to their most frequently reported race/ethnicity, assuming variations in race/ethnicity were in error. Individuals with different race/ethnicity reported an equal number of times across hospitalizations or visits were assigned to the other group.

**Co-morbidities.** Co-morbidities were defined based upon secondary diagnoses reported in the index admission. The most frequently reported comorbidities were selected for analysis. These comorbidities included hypertension, depression, drug abuse, pulmonary disease and fluid and electrolyte disorders. Depression and drug abuse were not included in the analysis of the index hospitalization because these diagnosis were very infrequent. All comorbidities were developed using the Healthcare Cost and Utilization Project (HCUP) co-morbidity software

47

version 3.7 provided for free on the internet.<sup>3</sup> OSHPD EDD data do not include DRGs used by the HCUP software to create comorbidity measures.

Language fluency was also explored, but this preexisting OSPHD variable lack variation. The majority of individuals in the sample were English speaking (approximately 98% in both PDD and EDD data sets).

**Route of admission.** Route of admission was selected from the original data. It is a binary variable of admission through the ED (reference) versus no ED or another facility's ED, controlling for urgent versus scheduled hospitalizations. Route of admission was not included in the count of ED analysis.

**Year of admission.** Year of admission (2006 (reference), 2007, 2008, 2009, 2010, 2011) was included in the readmission and length of stay analyses to control for possible historical changes or gradual decline in health due to ageing or disease progression, such as insurance or hospital delivery policies that would affect hospital utilization in the state. Hospitalizations with admission dates in December of 2005 and discharge dates in January 2006 were included in the 2006 category.

**Visit number**. Visit number was created and included in the models to control for potential differences between patients who had single encounters versus many.

Table 5 in chapter 6 provides a summary of variables included in each analytic model and the specifications of the analytic models by outcome.

<sup>&</sup>lt;sup>3</sup> http://www.hcup-us.ahrq.gov/toolssoftware/comorbidity/comorbidity.jsp

## **CHAPTER 6: EMPIRICAL METHODS**

This chapter outlines the statistical analyses used to test the hypotheses stated in chapter four. Part one discusses the general statistical analysis methods employed across models. Part two of this chapter discusses sensitivity analysis. Part three presents the specifications for each model to be analyzed.

### 6.1 Statistical Analyses

Data management and statistical analyses were performed in SAS 9.2 and Stata 12. The program and procedures used for each analysis are further described below. To provide context to the rate of SCD hospitalizations and ED use in California, an estimate of SCD patients in California ages 14-26 was calculated. This estimate was calculated by taking the 2005-2007 projected number of SCD patients in the state of California[63] and multiplying it by the estimated percent of the population between 14 and 26, the age range for patients examined in this study.

Descriptive bivariate analyses were conducted to examine the association of hospitalization outcomes (dependent variables) and primary predictors of interest. This descriptive work provides a preliminary assessment of the association of primary predictors of interest with hospitalization patterns and ED utilization. In addition, prior to developing analytic models, the correlations among all independent variables (individual and contextual) were examined to determine feasibility of including them simultaneously in any given model (Figure 3-6 in Appendix A). Four primary regression analyses were carried out during this study. The models were used to examine the impact of primary predictors of interest on all dependent variables, with adjustments for patient clustering within hospitals or zip codes. Regression methods were selected based on the nature and expected distribution of the dependent variable. Table 5 summarizes the variables that were included in each model.

**Count of Index hospitalizations.** The nature of the index hospitalization makes for a very complex regression method. First, it is a count variable, generally analyzed using Poisson or negative binomial regression. The choice of Poisson or negative binomial models depends on whether over-dispersion of the conditional variance is observed. Over-dispersion was found ( $\sigma 2$  =25,  $\mu$ =5) and using the Poisson model would likely produce wider-than-expected confidence intervals. In the case of over-dispersion, a negative binomial model is the preferred statistical method. Because the data only capture patients at the point of services, no individual patient had a count of zero for index admissions. A zero-truncated version of the negative binomial model was used to account for this truncation. The unit of analysis was at the patient level as described in chapter 5.

An analysis was conducted using the nlmixed procedure in SAS 9.2, specifying a negative binomial model. The nlmixed procedure fits mixed models in which the fixed or random effects are entered nonlinearly and fits models by maximizing an approximation to the likelihood integrated over the random effects. Applying random effects by hospital addresses the correlation within hospitals. A negative binomial model was specified using this procedure.

The sample included 308 hospitals out of approximately 400 California acute care hospitals. The sample also included 755 out of 2,591 zip codes. Patients were clustered within

hospitals and zip codes, and a multi-level modeling was the chosen method to control for clustering.

A design effect for zip code level and hospital level variables was calculated to test the degree of non-independence at these two separate levels. A design effect  $\geq 2$  was found, confirming the need to control for clustering at both levels. A design effect  $\geq 2$  for both levels of data required controlling for patients clustering within hospitals separately from a model that controls for patients clustering within residential zip codes. Including both simultaneously produced unbiased measures of dispersion and standard errors.

A truncated negative binomial regression was conducted specifying the likelihood function using nlmixed in SAS. The probability that an observation has a given count of hospitalizations under the negative binomial distribution without zero truncation is given by the equations (1)- $(5)^4$ :

(1)  $P(Y=y)=((y+1\alpha-1)/(1/\alpha-1))(1/1+\alpha\mu)1\alpha(\alpha\mu/1+\alpha\mu)y$ , where  $\alpha$  is the overdispersion parameter and  $\mu$  is the mean of the negative binomial distribution.

Since this distribution uses zero truncation, the probability that (Y=y) is conditional on Y>0 where 0 values are not observed. The probability of a zero count under the negative binomial is:

(2)  $P(Y=0)=(1/1+\alpha\mu)1\alpha$ 

<sup>&</sup>lt;sup>4</sup> SAS Data Analysis Examples Zero-Truncated Negative Binomial. Access on March 11, 2014. Available at http://www.ats.ucla.edu/stat/sas/dae/ztnb.htm

The conditional probability is:

(3) 
$$P(Y=y|Y>0) = P(Y=y)/P(Y>0) = P(Y=y)/1-P(Y=0) = ((y+1/\alpha-1)/(1/\alpha-1)) (1/(1+\alpha\mu))1\alpha$$
  
 $(\alpha\mu/1+\alpha\mu)y 1/(1-(1/1+\alpha\mu)1/\alpha)$ 

The log-likelihood function for the zero-truncated negative binomial distribution is thus:

(4) L=n (i=1)
$$\sum$$
i=1nlog $\Gamma$ (y+1/ $\alpha$ )-log $\Gamma$ (y+1)-log $\Gamma$ (1/ $\alpha$ )-1/ $\alpha$ log(1+ $\alpha\mu$ )+ylog( $\alpha\mu$ )-ylog(1+ $\alpha\mu$ )  
-log(1-(1+ $\alpha\mu$ )-1/ $\alpha$ ).

Negative binomial regression models,  $log(\mu)$ , the log of the mean (expected counts), as a linear combination of a set of predictors:

(5)  $\log(\mu) = \beta 0 + \beta 1$  age group +  $\beta 1$  proportion of days +  $\beta 3$  poverty status +  $\beta 4$  insurance status +  $\beta 5$  distance from hospital +  $\beta 6$  county of residence + +  $\beta 7$  gender +  $\beta 8$  race/ethnicity +  $\beta 9$  comorbidities + +  $\beta 10$  year + +  $\beta 11$  insurance switching +  $\beta 12$  hospital switching

The SAS syntax written to test this model is provided in Appendix A. Additional information on methods is available in the SAS/Stat user guide where details on the nlmixed procedure are provided.<sup>5</sup>

**Thirty-day Readmission.** The unit of analysis for the likelihood of a readmission was index hospitalizations. Seventy-five percent of all hospitalizations were index hospitalizations, and the remainder was thirty-day readmissions. An analysis was conducted using a multilevel logistic regression procedure in Stata 12.

Hospitalizations are clustered within patients and patients are clustered within hospital and residential zip codes. The use of a three-level multi-level model was explored but did not

<sup>&</sup>lt;sup>5</sup> <u>http://support.sas.com/rnd/app/stat/procedures/nlmixed.html</u>

significantly change the estimates on the four predictors of primary interest compared to a twolevel model. Potential clustering of visits within individuals was addressed by the addition of visit number for each index hospitalization. A design effect of less than two at the zip code level suggested that not enough non-independence existed at this level to justify cluster correction for zip code.

The full regression model for this analysis is specified in equation (6) below:

(6) Logc(y) = β0 + β1age group + β2poverty status + β3insurance status + β4distance from hospital + β5place of residence + β6hospital type+ β7gender + β8race/ethnicity + β9comorbidities + β10admission route + β11year + β12visit number + β13insurance switching + β14hospital switching + β 15\*primary diagnosis + ε

**LOS.** LOS is a count of days in the hospital from admission date to discharge date. The unit of analysis was all SCD hospitalizations. As a count model, it was analyzed using the xtgee procedure. The conditional distribution of LOS was examined for over-dispersion by obtaining the conditional mean and variance to determine the appropriateness of using a Poisson count model. The conditional variance ( $\sigma 2$ = 62) was ten times greater than the mean ( $\mu$ =6); demonstrating over-dispersion.

Multiple hospitalizations per patient were observed in the data. A generalized estimating equation (GEE) (adjusted for the panel nature of the data) with negative binomial indicated for family and link was deemed suitable for the analysis of LOS. The hospital was chosen as the higher order variable because the calculated design effect was greater than 2. The design effect for zip code was less than 2.

A working correlation structure is specified in GEE regression analysis. Exchangeable, Unstructured, Auto Regressive with lag one (AR(1) intracluster correlation), and Independent structures were tested. Exchangeable, also known as compound symmetry, is appropriate for models with no time order. Unstructured imposes no preconceived notions about the correlations among the responses over time. AR(1) is typically appropriate for repeated measure in which observations within individuals are related. An Independent structure assumes that the individual's observations are unrelated. A Quasi-Likelihood Information Criterion (QIC) value was calculated to determine which structure would be the preferred specification. The QIC value for exchangeable was 9306.845 and 9205.082 for AR(1). Convergence was not achieved when specifying unstructured. Correlation structures associated with low values of the QIC would be preferred. The QIC was lowest for the independent correlation structure (QIC=9121.483). Because the admissions are time sequenced, the analysis was conducted using both an independent and AR(1) correlation structure. Results were similar and results are presented from analyses using the independent correlation structure favored by the QIC criterion.[64]

An analysis was conducted using STATA 12. In this model, there are ni measurements on subject i as  $\sum_{i=1}^{K} n_i$ . That is yij, j=1,...ni, i=1,...,K represents the jth measurement on the ith subject. The vector of measurements on the *i*th subject is  $\mathbf{Y}_i = [y_{i1}, \dots, y_{in_i}]'$  with corresponding vector of means of  $\boldsymbol{\mu}_i = [\mu_{i1}, \dots, \mu_{in_i}]'$ .  $\mathbf{V}_i$  is the covariance matrix of  $\mathbf{Y}_i$  and the vector of independent variables on the jth measurement on the ith subject is  $\mathbf{x}_{ij} = [x_{ij1}, \dots, x_{ijp}]'$ . The generalized estimating equation of Liang and Zeger for estimating this correlation data model is<sup>6</sup>:

(7) 
$$\mathbf{S}(\boldsymbol{\beta}) = \sum_{i=1}^{K} \mathbf{D}'_{i} \mathbf{V}_{i}^{-1} (\mathbf{Y}_{i} - \boldsymbol{\mu}_{i}(\boldsymbol{\beta})) = \mathbf{0} \text{ where}$$
(7) 
$$\mathbf{D}_{i} = \frac{\partial \boldsymbol{\mu}_{i}}{\partial \boldsymbol{\beta}} \text{ since}$$
(9) 
$$g(\boldsymbol{\mu}_{ij}) = \mathbf{x}_{ij}' \boldsymbol{\beta}$$

In equation 9,  $\mathbf{g}$  is the link function and the  $P \times n_i$  matrix of partial derivatives of the mean with respect to the regression parameters for the *i*th subject is:

(10)  

$$\mathbf{D}'_{i} = \frac{\partial \boldsymbol{\mu}'_{i}}{\partial \boldsymbol{\beta}} = \begin{bmatrix} \frac{x_{i11}}{g'(\boldsymbol{\mu}_{i1})} & \cdots & \frac{x_{ini1}}{g'(\boldsymbol{\mu}_{ini})} \\ \vdots & \vdots \\ \frac{x_{i1p}}{g'(\boldsymbol{\mu}_{i1})} & \cdots & \frac{x_{inip}}{g'(\boldsymbol{\mu}_{ini})} \end{bmatrix}$$

The independent correlation structure is given by equation 11.

$$\operatorname{Corr}(Y_{ij}, Y_{ik}) = \begin{cases} 1 & j = k \\ 0 & j \neq k \end{cases}$$

<sup>&</sup>lt;sup>6</sup> SAS/STAT<sup>®</sup> 9.2 User's Guide, Second Edition. Generalized Estimating Equation. Accessed on May 13, 2014. Available at

https://support.sas.com/documentation/cdl/en/statug/63033/HTML/default/viewer.htm#statug\_genmod\_sect04 3.htm

**Count of ED visits.** The ED model was developed in the same manner as the index hospitalization model. Multi-level zero-truncated negative binomial models were developed for clusters of patients within hospitals and clusters of patients within zip codes. In this model, 27 extreme outliers of high ED utilization defined as over 100 visits, 1% of the sample, were dropped from the regression analysis. These high-utilizers with sparse data points were removed from the rest of the distribution because it was suspected that some other process generated them other than what was being modeled. Data exploration showed that observations with the same rln had matching gender and age at January 1, 2006. Yet, a lack of convergence in the model was a key deciding factor in the decision to drop. The ED model is estimated using equations (1)-(4) and equation (12) below. An analysis was conducted using the nlmixed procedure in SAS 9.2.

(12)  $\log(\mu) = \beta 0 + \beta 1 \text{age group} + \beta 1 \text{proportion of days} + \beta 3 \text{poverty status} + \beta 4 \text{insurance status} + \beta 5 \text{distance from hospital} + \beta 6 \text{county of residence} + \beta 7 \text{gender} + \beta 8 \text{race/ethnicity} + \beta 9 \text{year} + \beta 10 \text{insurance switching} + \beta 11 \text{hospital switching}$ 

## 6.2. Sensitivity Analysis in Count of Index and ED visit models

Three additional analyses were performed to test whether the model was sensitive to modifications to two variables that vary across patient observations, insurance status and comorbidities. The index hospitalization and ED visit model includes a measure of insurance status as reported at the last hospitalization. In the first sensitivity analysis, this measure was replaced with insurance status at the first hospitalization to observe how sensitive the estimates
or inferences were to this modification. Whether or not specifying the individual's first insurance status observable in the study period compared to their final insurance status changed the effect on the counts of the dependent variable was tested. In the second sensitivity analysis, insurance status remained at the last hospitalization and individual comorbidities were replaced with a binary variable for any comorbidity listed for each patient across all their hospitalizations. In the third sensitivity analysis, insurance status remained at the last hospitalization but comorbidity was dropped. For count of ED visits analysis on the first sensitivity analysis was performed.

	Statistical Model				
Variable List	Count of Index hospitalizations	30 day Readmit	LOS	Count of ED visits	
Primary Predictors of Interests					
Age Group		Х	Х		
Age Group on Jan 1, 2006	X			X	
Proportion of Days Observed	X			X	
Poverty Status	Х	Х	Х	Х	
Insurance Status *	X	Х	Х	X	
Insurance Switching**	X	Х	Х	X	
Contextual Variables					
Place of Residence	Х	Х	Х	X	
Hospital Type*	Х	Х	Х	X	
Hospital Switching**	Х	Х	Х	Х	
Independent Variables					
Primary Diagnosis of SCD		Х	Х		
Gender	X	Х	Х	X	
Race/Ethnicity	Х	Х	Х	X	
Common Comorbidities					
Hypertension	Х	Х	Х		
Pulmonary Disease	Х	Х	Х		
Fluid and Electrolyte Disorders	Х	Х	Х		
Depression***		Х	Х		
Drug Abuse***		Х	Х		
Route of Admission	X	Х	Х		
Year of Admission or Visit	Х	X	Х	X	
Visit Number		X	Х		
Sensitivity Analysis					
First Hospitalization Insurance Status	x			x	

# Table 5: Summary of Variables Included by Statistical Model

\* For the thirty-day readmission analysis, insurance status and hospital type were that reported on index hospitalizations. For the length of stay analysis, insurance status and hospital type were that reported on the admissions being analyzed. For the analysis of counts of index hospitalizations and ED visits, insurance status and hospital type were taken from each individual's last hospitalization.

\*\*For the analysis of counts of index hospitalizations or ED visits any insurance or hospitals change over the six years resulted in this variable being coded yes. For the analysis of thirty-day readmission and LOS, the variable was coded yes if there was a change in insurance status or treating hospital since the prior admission or visit. This variable was set to no for the first hospitalization or ED visit.

\*\*\*Depression and drug use were excluded in count of index hospitalization model due to small cell sizes.

# 6.3 Analytical Model Illustrations

The models (Figures 7-10) below summarize the hypothesized relationships between each dependent variable and the independent variables included in each analysis. The symbol (+) indicates a positive association with the dependent variable. The symbol (-) indicates a negative association with the dependent variable. A1 and B1 refer to the hypotheses. Letter prime refers to variables that were reserved for sensitivity analyses corresponding to the matching hypotheses. Dashed line refers to potential interactions tested for correlation (figures 3-6) but not tested in the regression analysis. For example, in figure 7, age is positively associated with increased expected count of index hospitalizations and the likelihood of having comorbidity may increase with age and treatment in a children's hospital decreases with age.

## Figure 7: Analytic Model for Count of Index Hospitalizations



A1: Being over the age of 20 (age-cut off for CCS) will be associated with greater number of index hospitalizations.

B1: Being uninsured, longer travel distance to the nearest hospital, and higher poverty will be associated with greater number of index hospitalizations.

## Figure 8: Analytic Model for 30 Day Readmissions



A1: Being over the age of 20 (age-cut off for CCS) will be associated with higher odds of a readmission.

B1: Being uninsured or underinsured, shorter travel to the nearest hospital, lower income and higher poverty will be associated with higher odds of a readmission.





A1: Being over the age of 20 (age-cut off for CCS) will be associated with longer length of stay.

B1: Being insured, longer travel distance to the nearest hospital and higher poverty will be associated with longer length of stay.





A1: Being over the age of 20 (age-cut off for CCS) will be associated with greater number of ED visits.

B1: Being uninsured, shorter travel distance to the nearest hospital, and higher poverty will be associated with greater number of ED visits.

#### **CHAPTER 7: RESULTS**

This chapter describes the results of the statistical analyses. Descriptive data is discussed first then multivariate regression analysis results. Regression results are present in the same order of discussion as they were introduced in chapter 6. Part one is an overview of general characteristics of patients and their hospitalizations and ED visits. Part two of this chapter provides the results of the count of index hospitalization analysis. Part three shows the results of the readmission analysis. Part four is LOS and part five the count of ED visits analysis is discussed.

#### 7.1 General Characteristics of Patients, Hospitalizations, and ED Visits:

## 7.1.1 Descriptive Analysis:

**Patient Discharge Data (2006-2011).** Six years of OSHPD inpatient discharge data included greater than 24 million hospitalizations. Following the process of SCD sample selection described in Figure 2, 1,825 patients were identified with 13,257 hospitalizations (Table 6).

Existing estimates indicate that 5,773 SCD patients reside in the state of California per year [63] and 64% or 3,695 of these patients are under age 30.[65] The size of the population of SCD patients within the study age range of 14-26 was estimated as 13/30ths of the 3,695 patients under 30, or approximately 2,500. Thus, approximately 73% of SCD patients age 14-26 were hospitalized at some point over the 6 years studied and observed in this study.

Seventy-three percent of the selected hospitalizations in this study were identified with a primary diagnosis of SCD, 23% with a secondary SCD diagnosis (Table 6). Four percent of hospitalizations did not have a SCD diagnosis but were included because the rln on the hospitalization matched a rln for hospitalizations identified with a primary or secondary SCD diagnosis (in step one and two of selection process). The average count per patient was seven hospitalizations (including index and readmissions) during the study timeframe. Index hospitalizations were 62% of all hospitalizations included in this study. The remaining hospitalizations were considered 30 day readmissions. Mean LOS for the full sample was 6.2 days with a standard deviation of 7.9 days. The mean average percent was 43% below 200 FPL.

# Descriptive Summary at Hospitalization Level. Eighty-seven percent of

hospitalizations were at general hospitals, 13% at children's hospitals. A hospital switch from previous admission occurred in 26% of hospitalizations.

	n	Percent (%)
Sickle Cell Sample		
Primary Diagnosis	9,629	73
Secondary Diagnosis	3,090	23
Hospitalizations with Matching RLN	556	4
Hospitalizations		
Index Inpatient Visits	8,275	62
Inpatient Readmissions	5,054	38
Length of Stay (mean, SD)	6.2	7.9
Characteristics of Hospitalized Patients		
Age Group		
14-17	2,344	18
18-20	3,382	24
21-26	7,631	56

#### Table 6: Descriptive Statistics of Hospitalizations and Demographics between 2006 and 2011, at Hospitalization Level. (N=13.257)

Poverty Status (Percent Below FPL within Zip Code)	n	Percent (%)
0-24% (reference)	1,966	15
25-49%	6,767	51
≥50%	4,473	34
Insurance Status		
Medicare	1,222	9
Medicaid/Other Government	8,717	66
Private	2,738	21
Uninsured	580	4
Distance from home to nearest hospital	7	00
in miles*	1	89
Individual-Level Characteristics		
Gender		
Male	5,979	45
Female	7,278	55
Race/ethnicity		
African American	12,330	93
Latino	441	3
Other	486	4
Most Common Co-morbidities**		
Hypertension	5,976	45
Pulmonary Disease	2,271	17
Fluid and Electrolyte Disorders	1,371	10
Depression	638	5
Drug Abuse	825	6
Route of Admission		
ED	10,048	76
non-ED/another Hospital ER	3,209	24
Year of Admission		
2006	2, 267	17
2007	2,030	15
2008	2,087	15
2009	2,324	18
2010	2,271	17
2011	2,278	17
Insurance Switching from previous hospitalization	1,766	13
Hospital Switching from previous hospitalization	3,491	26

Place of Residence	n	Percent (%)
LA County	5,348	40
Southern California	3,579	27
Central California	490	4
Northern California	3,840	29
Hospital Type		
General Hospital	11,218	85
Children's Hospital	2,039	15

#### **Contextual-Level Characteristics**

\* Mean and standard deviation is displayed

\*\*Common Comorbidities were not mutually exclusive. Patients could have more than one condition.

**Description of Excluded Observations**. After selecting the hospitalizations of 14-26 year olds with primary and secondary diagnosis of SCD, observations with missing patient identifiers (rln) were excluded (Figure 2). Table 7 provides the characteristics of the excluded observations. Hospitalizations that did not have a SCD diagnosis but had a matching patient identifier to another hospitalization with primary or secondary SCD diagnosis were only included in the main analysis. Insurance switching and hospital switching variables could not be created for patients with missing rln.

The age distribution of excluded hospitalizations was somewhat different from included hospitalizations. More hospitalizations without rln were for individuals ages 14-17 and fewer were for individuals ages 21-26 than hospitalizations with rln. Average poverty status was similarly distributed. Females were slightly more represented in the excluded cases. Excluded cases were only African Americans. Only 1% of the excluded cases were on Medicare compared to 9% of the included hospitalizations. Uninsured and private insurance was more represented in the excluded cases and Medicaid/other government less represented. Non-Ed route of

admissions were more frequent in the excluded cases. Year of admission and hospital type distributions were similar to the included cases. The only place of residence observed among the excluded cases was the Northern California region.

Characteristics of Hospitalized Patients	n	Percent (%)
Age Group		
14-17	303	29.5
18-20	264	25.7
21-26	458	44.7
Poverty Status (Percent Below FPL within Zip Code)		
0-24% (reference)	185	18
25-49%	518	50.9
≥50%	315	30.9
Insurance Status at hospitalization		
Medicare	10	1.0
Medicaid/Other Government	580	56.6
Private	336	32.8
Uninsured	99	9.7
Individual-Level Characteristics		
Gender		
Male	597	41.7
Female	428	58.2
Race/Ethnicity		
African American	1.025	100
Latino	0	0
Other	0	0
Route of Admission		
ED	715	69.8
non-ED/another Hos ER	310	30.2
Year of Admission		
2006	133	13
2007	166	16
2008	177	17
2009	197	19

Table 7: Patient Characteristics of Excluded Hospitalizations (n=1,025).

	n	Percent (%)
2010	16	16
2011	186	18
Contextual-Level Characteristics		
Place of Residence		
LA County	0	0
Southern California	0	0
Central California	0	0
Northern California	1,025	100
Hospital Type		
General Hospital	822	80.2
Children's Hospital	303	19.8

**Descriptive Statistics by Age.** Table 8 provides descriptive statistics of insurance by age at admission. For patients hospitalized before age 18, the most common forms of expected source of insurance were Medicaid/other government and private. Very few patients between the ages of 14-17 were uninsured at the time of hospitalization. At age 18 the most common expected source of insurance was still Medicaid and private coverage. However, the percent uninsured increased and continued to increase up to age 26. For patients hospitalized at age 21, there was shift from Medicaid to Medicare or uninsured.

Age in Years	Medicare	Medicaid/Other Government	Private	Uninsured	By Age Total
14	0(0)	331(72)	130(28)	1(0.2)	462
15	0(0)	339(66)	170(33)	4(0.8)	513
16	0(0)	422(70)	175(29)	6(1.0)	603
17	0(0)	542(71)	210(27)	14(2)	766
18	0(0)	720(73)	246(25)	22(2)	988
19	3(0.3)	830(75)	242(22)	36(3)	1,111
20	72(6)	795(67)	267(23)	49(4)	1,183
21	129(10)	863(65)	267(20)	76(6)	1,335
22	145(11)	866(65)	223(17)	84(6)	1,318
23	194(15)	845(64)	210(17)	79(6)	1,328
24	202(17)	748(62)	201(17)	63(5)	1,214
25	220(18)	697(58)	200(17)	57(7)	1,206
26	257(21)	719(59)	197(16)	57(5)	1,230
All Ages	1,222	8,717	2,738	580	

Table 8: Age Group by Insurance at Hospitalization Level (sample size by age (percent by age)).

The oldest age group had higher average hospitalizations, average index hospitalizations, average number of readmissions and average LOS (Table 9). The youngest age group had the highest percent of hospitalizations with readmissions. A greater percentage of those residing in the highest percent average poverty zip codes were from patients 21-26 years old. Insurance switching and hospital switching was more often in patients 21-26. The mean distance from home to nearest hospital was greatest in the middle age group, 18-20 and similar among 14-17 and 21-26 year olds.

	A	Age Grou	р
	14-17	18-20	21-26
Hospitalizations			
Average number of hospitalizations	5	10	16
Average number of index hospitalizations	3	3	4
% of index hospitalizations with readmissions	19	15	16
Average number of readmissions	1	2	4
Average LOS	5.4	5.9	6.5
% in Poverty Status Groups			
0-24%	18	15	14
25-49%	54	52	50
≥50%	28	33	36
Mean distance from home to nearest hospital (in miles)	4	12	6
% Insurance switching from previous hospitalization	7	13	16
% Hospital switching from previous hospitalization	11	26	31

 Table 9: Descriptive Statistics of Hospitalizations, Poverty, Distance, and Switching by Age
 Group.

**Emergency Department Data.** Six years of OSHPD ED data included approximately 57 million ED visits. The ED dataset included 17,047 SCD visits for 2,013 patients (Table 10). The number of ED visits increased to 24,890 when hospitalizations that started with ED visits were added to the sample. Sixty-four percent of the ED visits were identified with a primary diagnosis of SCD, 22% with a secondary SCD diagnosis. Fifteen percent of visits did not have a SCD diagnosis but were included because the rln on the hospitalization matched an rln for hospitalizations identified with a primary or secondary SCD diagnosis.

	n	Percent (%)
Sickle Cell Sample		
Primary Diagnosis	15,828	64
Secondary Diagnosis	5,450	22
Hospitalizations with Matching RLN	3,678	15
Characteristics of Patients		
Age Group		
14-17	2,796	11
18-20	5,756	23
21-26	16,338	66
Poverty Status (Percent Below FPL within Zip Code)		
0-24% (reference)	3,160	13
25-49%	12,511	50
$\geq$ 50%	9,123	37
Insurance Status		
Medicare	2,020	8
Medicaid/Other Government	15,895	64
Private	4,670	19
Uninsured	2,305	9
Distance from home to nearest hospital in miles*	4	9
Individual-Level Characteristics		
Gender		
Male	12,987	52
Female	11,903	48
Race/ethnicity		
African American	3,160	13
Latino	12,511	50
Other	9,123	37
Year of Admission		
2006	3,831	15
2007	3,878	16
2008	3,952	16
2009	4,366	17
2010	4,357	18
2011	4,506	18
Insurance Switching from previous hospitalization	4,508	18
Hospital Switching from previous hospitalization	8,349	34

# Table 10: Descriptive Summary of Emergency Department Utilization between 2006 and 2011 at Visit Level. (N=24,890)

# Contextual-Level Characteristics

Place of Residence		
LA County	9,987	40
Southern California	6,503	26
Central California	1,037	4
Northern California	7,363	30

Hospital Type	n	Percent (%)
General Hospital	22,384	90
Children's Hospital	2,506	10

\*Mean and standard deviation is displayed

**Description of ED Excluded Observations**. After selecting the hospitalizations of 14-26 year olds with primary and secondary diagnosis of SCD, observations with missing patient identifiers (rln) were excluded (Figure 2). Table 11 provides the characteristics of the excluded observations. Hospitalizations that did not have a SCD diagnosis but had a matching patient identifier to another hospitalization with primary or secondary SCD diagnosis were included in the main analysis. Table 11 describes the characteristics of excluded ED observations. In the main analysis, hospitalizations that did not have a SCD diagnosis but a matching patient identifier to a hospitalizations that did not have a SCD diagnosis but a matching patient identifier to a hospitalization with primary or secondary diagnosis were included. In the case of excluded observations, these hospitalizations were not selected because of the missing patient identifier (rln). Insurance switching and hospital switching variables could not be created for patient with missing rln.

In comparison to the included ED visits, the age group distribution was more spread out across age groups. While ED visits still increased by age group, the differences in percentage was smaller than that seen between included cases. Average poverty status was similarly distributed. Females were slightly more represented in the excluded cases. Only African Americans were identified. Only half a percent of the excluded cases were on Medicare compared to 8% of the included hospitalizations. Uninsured and private insurance was more represented in the excluded cases and Medicaid/other government less represented. Slightly more visits occurred in year 2009 and 2011 compared to included visits. The hospital type

distribution was similar to the included cases. The only place of residence observed among the excluded cases was the Northern California region.

Characteristics of Patients	n	Percent (%)	
Age Group			
14-17	291	22	
18-20	338	26	
21-26	666	51	
Poverty Status (Percent Below FPL within Zip Code)			
0-24% (reference)	218	17	
25-49%	789	63	
≥50%	244	20	
Insurance Status at hospitalization			
Medicare	7	0.5	
Medicaid/Other Government	418	32	
Private	326	25	
Uninsured	544	42	
Individual-Level Characteristics			
Gender			
Male	635	49	
Female	660	51	
Race/Ethnicity			
African American	1,295	100	
Latino	0	0	
Other	0	0	
Year of Admission			
2006	127	10	
2007	170	13	
2008	228	18	
2009	273	21	
2010	213	16	
2011	284	22	
Contextual-Level Characteristics			
Place of Residence			
LA County	0	0	
Southern California	0	0	

Table 11: Patient Characteristics of Excluded ED Visits (n=1,295).

	n	Percent (%)
Central California	0	0
Northern California	1,295	100
Hospital Type		
General Hospital	13,070	9
Children's Hospital	1,262	91

**Descriptive Statistics by Age.** Table 12 provides descriptive statistics of insurance by age at visit. For patients visiting the ED before age 18, the most common forms of expected source of insurance were Medicaid/other government and private. Very few patients between the ages of 14-17 were uninsured at the time of hospitalization. At age 18 the most common expected source of insurance was still Medicaid, but the proportion of privately insured decreased. The percent uninsured increased and continued to increase up to age 26. For patients hospitalized at age 21, a shift from Medicaid to Medicare or uninsured was observed up until age 26.

Age in Years	Medicare	Medicaid/Other Government	Private	Uninsured	By Age Total
14	0(0)	400(79)	99(20)	9(1.8)	508
15	0(0)	409(72)	137(24)	20(3.5)	566
16	1(0.1)	556(75)	160(21)	28(3.7)	745
17	3(0.3)	654(67)	282(29)	38(3.9)	977
18	8(0.5)	1,090(70)	371(24)	94(6.0)	1,563
19	8(0.4)	1,387(69)	452(23)	155(7.7)	2,002
20	107(4.8)	1,475(67)	449(20)	160(7.3)	2,191
21	232(11.5)	1,733(62)	535(19)	278(10.0)	2,778
22	252(9)	1,775(64)	500(18)	251(9.0)	2,778
23	331(11.9)	1,743(62)	443(16)	277(9.9)	2,794
24	343(17)	1,677(62)	429(16)	269(9.9)	2,718
25	339(13)	1,497(58)	374(14)	392(15)	2,602
26	396(15)	1,499(56)	439(16)	334(13)	2,668
All Ages	2,020	15,895	4,670	2,305	

Table 12: Age Group by Insurance (sample size by age( percent by age)) at ED Visit Level.

The 21-26 year old age group had higher average visits than 18-20, or 14-17 (Table 13). A greater percentage of those residing in the highest percent poverty group were from patients 21-26 years old. Insurance switching and hospital switching was more often in patients 21-26. The mean distance from home to nearest hospital was greatest among 18-20 and the distance was similar between 14-17 and 21-26 year olds.

# Table 13: ED Descriptive Statistics Poverty,Distance, and Switching by Age Group.

	Age Group					
	14-17	18-20	21-26			
ED Outcomes						
Average number of ED visits	15	38	85			
Poverty Status (Percent Below FPL within Zip Code)						
0-24%	15	13	12			
25-49%	54	54	49			
≥50%	31	34	39			
Mean Distance from home to nearest hospital						
(in miles)	4	9	5			
% Insurance Switching from previous hospitalization	12	18	19			
% Hospital Switching from previous hospitalization	17	32	37			

# 7.2 Count of Index Hospitalization:

# 7.2.1 Descriptive Analyses

Count of index hospitalizations was assessed at the patient level. Table 14 includes

descriptive statistics for the variables used in the analysis of the count of index hospitalizations.

n	Percent (%)
1,045	57
696	38
84	5
7	11
882	49
	n 1,045 696 84 7 882

# Table 14: Descriptive Statistics of Inpatient Utilization between 2006 and 2011 at Individual Level (Index Analysis (N=1.825))

	n	Percent (%)
18-20	405	22
21-26	538	29
Proportion of Days		
Observed*	0.82	0.26
Poverty Status (Percent Below FPL within Zip Code)		
0-24%	309	17
25-49%	931	51
$\geq$ 50%	580	32
Insurance Status at First Observation		
Medicare	76	4
Medicaid/Other Government	1,015	56
Private	551	30
Self-Pay/Other/Unknown	183	10
Distance to the nearest hospital in 100th of a mile*	0.7	0.9
Individual-Level Characteristics		
Gender		
Male	742	41
Females		
Race/ethnicity		
African American	1,626	89
Latino	81	4
Other	118	7
Most Common Co-morbidities		
Hypertension	900	49
Pulmonary Disease	323	18
Fluid and Electrolyte Disorders	217	12
Year of Admission		
2006	200	11
2007	195	11
2008	209	11
2009	247	14
2010	289	16
2011	685	38
Any Insurance Switching	371	20
Any Hospital Switching	729	40

# **Contextual-Level Characteristics**

Country of Residence	n	Percent %
LA County	675	37
Southern California	495	27
Central California	79	4
Northern California	576	32
Hospital Type		
General Hospital	1,585	87
Children's Hospital	240	13

\*Mean and standard deviation is displayed.

Thirty-seven percent (n=674 patients) only experience one index hospitalization over the six years of data. In the standardized age group variable for January 1, 2006, 14-17 was 49% of the sample, 18-20 was 29% and 21-26 was 22%.

Half of the patients had expected source of payment (insurance status) reported as Medicaid or other government. Twenty percent of patients had at least one insurance switch during the six year timeframe. Average distance to the nearest hospital was rescaled to 100<sup>th</sup> of a mile for model convergence. The mean distance was 0.7 miles. Half the index analytic sample resided in zip code areas of 25-50% average poverty level.

# 7.2.2 Adjusted Association of Index Hospitalizations with Age and SES:

Table 15 presents the analysis of the regression of the count of index hospitalizations on age, insurance status and other variables. The data show that age was a significant predictor, with those in the oldest age group in 2006 having an expected count of index hospitalizations 1.60 times greater than those in the youngest age group [95% CI: 1.34-1.95; p value=0.00]. However, those ages 18-20 did not differ from the youngest age group.

Patients with private insurance [IRR = 0.67; 95% CI: 0.58-0.78; p value=0.00] or the uninsured [IRR =0.34; 95% CI: 0.27-0.44; p value=0.00] had a significantly lower expected count of index hospitalizations than those with Medicaid. If the patient experienced a switch in insurance they had an expected count of index hospitalizations of 1.67 times greater than those who had the same coverage for all reported hospitalizations.

The categories of average poverty status at zip code of residence were not significantly associated with the count of index hospitalizations. Distance to nearest acute care hospital was also not significantly associated with index hospitalizations.

Among the individual level factors, males had a significantly higher expected count of index hospitalizations [IRR=1.14; 95% CI: 1.01-1.28; p value=0.04] compared to females. Those who were in the other category had a significantly lower expected count [IRR=0.70; 95% CI: 0.52-0.94; p value=0.02] compared to African Americans. Hypertension was associated with lower expected count [IRR=0.84; 95% CI: 0.73 -0.97; p value=0.02]. Pulmonary disease [IRR=1.52; 95% CI: 1.27-1.80; p value=0.00] and fluid and electrolyte disorder was associated with a higher expected count [IRR=1.27; 95% CI: 1.05-1.54; p value=0.02]. All categories of year of admission were significantly associated with higher expected counts compared to year 2006 [2007: IRR=2.41; 95% CI: 1.72-3.39; p value=0.00; 2008: IRR=2.25; 95% CI: 1.62-3.16; p value<0.00; 2009: IRR=3.74; 95% CI: 2.72-4.95; p value=0.00; 2010: IRR=4.81; 95% CI: 3.49-6.55; p value=0.00; 2011: IRR=9.12; 95% CI: 6.69-12.30; p value=0.00].

If the patient had switched hospitals, they had a higher expected index count of 2.66 than those who consistently presented at the same hospital [95% CI: 2.32-3.03; p value=0.00]. Place of residence was not a significant predictor of index hospitalizations.

# Table 15: Zero-Truncated Negative Binomial Adjusted Associations: Count of Index Hospitalizations and Sensitivity Analysis (Continued on the Next Page).

Independent Variables	Cour with 1	nt of Index Last Obser and Last ( Como	hospitali rvation In Dbservatio rbidities	zations surance on	Cour with I	nt of Index First Obse and Last ( Come	x Hospitali rvation Ins Observatio orbidity	zation surance n	Coun with I a	t of Index I Last Observ and Any Co	Hospitaliz ation Insu	ation trance	Coun with L a	t of Index ast Observ nd No Cor	Hospitaliz vation Ins morbiditie	zation urance es
	IRR	Lower	Upper	p value	IRR	Lower	Upper	p value	IRR	Lower	Upper	p value	IRR	Lower	Upper	p value
Age Group at January 1 2006			••				**				* *				••	
14-17 (reference)																
18-20	0.89	0.76	1.03	0.13	0.95	0.81	1.12	0.56	0.85	0.73	1.00	0.04	0.88	0.93	1.79	0.12
21-26	1.60	1.34	1.95	0.00	1.75	1.43	2.12	0.00	1.32	1.09	1.60	0.00	1.55	1.28	1.90	0.00
Proportion of Days Observed Poverty Status (Percent Below FPL within Zip Code)	1.35	0.84	1.88	0.06	1.35	0.74	1.86	0.07	1.07	0.78	1.48	0.66	1.30	0.93	1.79	0.12
0-24% (reference)																
25-49%	0.99	0.75	1.31	0.96	1.00	0.76	1.32	0.98	1.00	0.76	1.32	0.99	0.98	0.74	1.31	0.91
≥50%	1.03	0.74	1.43	0.85	1.05	0.75	1.46	0.78	1.06	0.74	1.48	0.72	1.03	0.74	1.45	0.84
Insurance Status																
Medicare	1.09	0.89	1.35	0.85	0.95	0.70	1.30	0.74	1.06	0.87	1.30	0.55	1.08	0.88	1.35	0.45
Medicaid/ Other Government (reference)																
Private	0.67	0.58	0.78	0.00	0.71	0.62	0.83	0.00	0.71	0.61	0.82	0.00	0.65	0.56	0.76	0.00
Uninsured	0.34	0.27	0.44	0.00	0.38	0.30	0.48	0.00	0.38	0.30	0.49	0.00	0.33	0.25	0.42	0.00
Distance from home to nearest hospital in 100th of a mile	0.99	0.91	1.07	0.84	0.98	0.90	1.06	0.62	0.98	0.90	0.94	0.61	0.99	0.83	1.07	0.82

Table 15: Zero-Truncated Negative Binomial Adjusted Associations: Count of Index Hospitalizations and Sensitivi	y Analysia	is (continued)
---	------------	----------------

Independent Variables	Cour Last	nt of Index Observation Observation	hospitalizat on Insurance on Comorbic	ions with and Last lities	Count First (	t of Index Observatio Observatic	Hospitaliza n Insurance n Comorbi	tion with e and Last dity	Count of Index Hospitalization with Last Observation Insurance and Any Comorbidity			Count of Index Hospitalization with Last Observation Insurance and No Comorbidities Lowe				
	IRR	Lower	Upper	p value	IRR	Lower	Upper	p value	IRR	Lower	Upper	p value	IRR	r	Upper	p value
Individual-Level Characteristics																
Gender																
Female (reference)																
Male	1.14	1.01	1.28	0.04	1.13	0.99	1.27	0.06	1.16	1.04	1.31	0.01	1.16	1.03	1.31	0.02
Race/ethnicity																
African American (reference)																
Latino	0.86	0.62	1.20	0.34	0.85	0.61	1.19	0.35	0.84	0.60	1.16	0.28	0.86	0.62	1.21	0.39
Other Common Comorbidities at Last Observation	0.70	0.52	0.94	0.02	0.66	0.49	0.89	0.01	0.76	0.56	1.00	0.05	0.69	0.51	0.93	0.02
Hypertension	0.84	0.73	0.97	0.02	0.49	0.73	0.98	0.03								
Pulmonary Disease	1.52	1.27	1.80	0.00	1.57	1.31	1.86	0.00								
Fluid and Electrolyte Disorders Any Comorbidities Across Hospitalizations	1.27	1.05	1.54	0.02	1.26	1.03	1.52	0.02	2.16	1.84	2.51	0.00				
Vear of Admission																
2006 (reference)																
2007	2.41	1.72	3.39	0.00	2.34	1.67	3.29	0.00	2.25	1.60	3.13	0.00	2.36	1.67	7.10	0.00
2008	2.25	1.62	3.16	0.00	2.16	1.54	3.03	0.00	2.20	1.58	3.10	0.00	2.29	1.63	3.19	0.00
2009	3.74	2.72	4.95	0.00	3.60	2.61	4.95	0.00	3.56	2.59	4.90	0.00	3.82	2.77	5.26	0.00
2010	4.81	3.49	6.55	0.00	4.71	3.42	6.55	0.00	4.35	3.16	5.93	0.00	4.85	3.53	6.75	0.00
2011	9.12	6.69	12.30	0.00	9.39	6.89	12.68	0.00	7.61	5.64	10.28	0.00	9.12	6.69	12.43	0.00
Any Insurance Switching	1.67	1.43	1.93	0.00	1.77	1.52	1.93	0.00	1.62	1.39	1.88	0.00	1.68	1.45	1.97	0.00
Any Hospital Switching	2.66	2.32	3.03	0.00	2.66	2.32	3.03	0.00	2.41	2.12	2.77	0.00	2.69	2.34	3.10	0.00

Independent Variables	Coun Last (	t of Index Observatio Observatio	hospitalizat n Insurance n Comorbic	ions with and Last lities	Coun First (	t of Index I Observation Observatio	Hospitaliza n Insuranco on Comorbi	ation with e and Last idity	Coun Last (	t of Index Observatio Con	Hospitaliza n Insurance norbidity	ation with e and Any	Count Last (	t of Index I Observatio Come	Hospitaliza n Insuranc orbidities	ation with e and No
	IRR	Lower	Upper	p value	IRR	Lower	Upper	p value	IRR	Lower	Upper	p value	IRR	Lower	Upper	p value
Place of Residence LA County (reference)																
Southern California	2.61	0.76	1.32	0.96	1.12	0.84	1.46	0.45	1.00	0.76	1.31	0.98	1.00	0.76	1.23	0.98
Central California	1.48	0.49	1.32	0.39	0.84	0.51	1.40	0.51	0.73	0.45	1.21	0.22	0.75	0.45	1.23	0.25
Northern California	1.72	0.69	1.21	0.54	0.94	0.71	1.13	0.7	0.90	0.68	1.21	0.51	0.93	0.70	1.25	0.63

#### Table 15: Zero-Truncated Negative Binomial Adjusted Associations: Count of Index Hospitalizations and Sensitivity Analysis (continued)

Effective Sample Size: 1,825 patients

#### 7.2.3 Count of Index Hospitalization Sensitivity Analysis:

Three additional analyses were performed to test whether the model was sensitive to variable specification and inclusion or exclusion of specific predictors that varied across patient observations. In the first sensitivity analysis, insurance status at last hospitalization was replaced with insurance status at first hospitalization. While the significance of age remained, the magnitude of the incidence rate ratio of 21-26 increased from 1.60 to 1.75 with significant overlap in the confidence intervals between the two models. The magnitudes of the coefficients for insurance status were similar with overlapping confidence intervals. Same was true for individual-level characteristics, contextual-level characteristics, insurance and hospital switching. However, the magnitude of comorbid condition hypertension decreased from 0.84 to 0.49 with similar significance and overlapping confidence intervals.

In the second sensitivity analysis, insurance status remained at the last hospitalization and individual comorbidities were replaced with the binary any comorbidity listed for each patient across all their hospitalizations. Any comorbidity was associated with higher expected count of index hospitalizations [IRR=2.16; 95% CI: 1.84-2.51; p value=0.00]. Compared to the original analysis each category of age remained significant but the magnitude of the incidence rate ratio on age 21-26 was lower at 1.32 with overlapping confidence intervals. Proportion of days observed was even less significant compared to the original model with a lower magnitude of effect. All other coefficients and p values were similar.

In the third sensitivity analysis, insurance status remained at the last hospitalization but comorbidity was dropped. All incidence rate ratio, confidence intervals, and p values were comparable to the original analysis.

Despite the modifications to the insurance and comorbidity variables, the direction of effect and magnitudes of incidence rate ratios, confidence intervals, and p values for the primary predictors of interest were similar in the original model to those estimated in the sensitivity analysis.

#### 7.3 Thirty Day Readmission

### 7.3.1 Descriptive Analyses

Thirty day readmission was assessed at the index hospitalization level. Table 16 includes descriptive statistics for the variables used in the analysis of thirty day readmission at the level of index hospitalizations.

	n	Percent (%)
Sickle Cell Sample		
Primary Diagnosis Visits	5,961	73
Secondary Diagnosis Visits	1,990	24
Hospitalizations with Matching RLN	266	3
Characteristics of Patients		
Age Group		
14-17	1,786	22
18-20	2,107	26
21-26	4,310	53

### Table 16: Descriptive Statistics For Sample Used in Readmission Analysis. (Index Hospitalization Level: N=8,203)

Poverty Status (Percent Below FPL		
within Zip Code)	n	Percent (%)
0-24% (reference)	1,321	16
25-49%	4,188	51
≥50%	2,669	32
Insurance Status		
Medicare	734	9
Medicaid/Other Government	5,140	63
Private	1,918	23
Uninsured	411	5
Distance to the nearest hospital		
in miles*	6	71
Individual-Level Characteristics		
Gender		
Male	3,612	44
Female		
Race/ethnicity		
African American	7,573	92
Latino	306	4
Other	324	4
Most Common Comorbidities*		
Hypertension	3,494	43
Pulmonary Disease	1,416	17
Fluid and Electrolyte Disorders	791	10
Depression	282	3
Drug Abuse	363	4
Route of Admission		
ED	6,126	75
Non-ED/another Hos ER		
Year of Admission		
2006	1,375	17
2007	1,285	16
2008	1,362	17
2009	1,495	18
2010	1,375	17
2011	1,311	16
Insurance Switching	3,009	37
Hospital Switching	5,260	64
Contextual-Level Characteristics		
Regional of Residence		
LA County	3,081	38
LA County	3,081	38

	n	Percent (%)
Southern California	2,276	28
Central California	349	4
Northern California	2,497	30
Hospital Type		
General Hospital	6,808	83
Children's Hospital	1,395	17

\*Mean and standard deviation is displayed

\*\*Common comorbidities were not mutually exclusive. Patients could have more than one condition.

Fifty-three percent of index hospitalizations were from patients 21-26, 14-17 was 22% of the sample, and 18-20 was 26%. The majority were African American (92%) and female (56%). Half the index hospitalization resided in zip code areas of 25-50% poverty level. Sixty-three percent of index hospitalizations had expected source of payment (insurance status) reported as Medicaid or other government. Twenty-three percent were hospitalizations from patient with private insurance. Thirty-seven percent had switched insurance during the study years. The mean distance to nearest hospitals was 6 miles. The majority (83%) were treated in general hospitals. Seventy-five percent were admitted through the ED. Sixty-four percent had switched hospitals during the study years. Thirty-eight percent of index hospitalizations were in Los Angeles County, 28% in the other counties of Southern California, 20% in Northern California.

The most common diagnoses reported if the index hospitalization was not due directly to sickle cell were pneumonia, organism not otherwise specified (8%), anemia-antepartum (10%), and anemia-delivered (3%).

Table 16b includes descriptive statistics of readmission. Sixty-six percent of readmissions were from patients 21-26, 14-17 was 11% of the sample, and 18-20 was 23%. The majority were African American (94%) and female (53%). Half the readmissions resided in zip code areas of 25-50% average poverty level.

Seventy-one percent of readmissions had expected source of payment (insurance status) reported as Medicaid or other government. Sixteen percent were readmissions from patient on private insurance. Thirteen percent were related to an insurance switch. The mean distance from to nearest hospitals was 9 miles. The majority (87%) were treated in general hospitals. Seventy-six percent were admitted through the ED. Thirty-five percent were related to a hospital switch. Forty-five percent of readmissions were from patients residing in Los Angeles county, 26% in the other counties of Southern California, 27% in Northern California, 3% in Central California.

Most common diagnoses reported at the first readmission after the index hospital was sickle cell crises or other types of sickle cell episodes (60%), anemia-antepartum (3%) and pneumomia (2.5%).

# Table 16b: Descriptive Statistics for Patients That Had Readmissions (N=5,054).

\_

	n	Percent (%)
Sickle Cell Sample		
Primary Diagnosis Readmissions	3,668	73
Secondary Diagnosis Readmissions	1,100	22
Readmissions with Matching RLN	290	6
Characteristics of Patients		
Age Group		
14-17	558	11
18-20	1,175	23
21-26	3,321	66
Poverty Status (Percent Below FPL within Zip Code)		
0-24%	645	13
25-49%	2,579	51
≥50%	1,804	36
Insurance Status	,	
Medicare	488	10
Medicaid/Other Government	3,577	71
Private	820	16
Uninsured	169	3
Distance to the nearest hospital in miles*	9	106
Individual-Level Characteristics		
Gender		
Male	2,367	47
Female	2,687	53
Race/ethnicity		
African American	4,757	94
Latino	135	3
Other	162	3
Most Common Comorbidities**		
Hypertension	2,482	49
Pulmonary Disease	855	17
Fluid and Electrolyte Disorders	580	11
Depression	356	7
Drug Abuse	462	9
Route of Admission		
ED	3,922	76
Non-ED/another Hos ER	1,132	22
	n	Percent (%)

Year of Admission		
2006	892	18
2007	745	15
2008	725	14
2009	829	16
2010	896	18
2011	967	19
Insurance Switching	679	13
Hospital Switching	1,786	35
Contextual-Level Characteristics		
Regional of Residence		
LA County	2,267	45
Southern California	1,303	26
Central California	141	3
Northern California	1,343	27
Hospital Type		
General Hospital	4,410	87
		10

\*Mean and standard deviation is displayed

\*\*Common comorbidities were not mutually exclusive. Patients could have more than one condition.

## 7.3.2 Regression Adjusted Association of Thirty Day Readmission:

Table 17 presents the analysis of the regression of the count of index hospitalizations on age, insurance status and other variable. In regression analysis of whether a thirty readmission occurred, age 21-26 was associated with having higher odds of a readmission than those in the youngest age group [OR= 1.14; 95% CI: 0.93-1.40; p value=0.02]. Ages 18-20 were not significantly different from ages 14-17. Having a primary diagnosis of SCD was associated with lower odds of readmission [OR= 0.84; 95% CI: 0.72-0.97; p value=0.02].

All insurance categories were associated with lower odds of having a readmission compared to Medicaid/other government [Medicare: OR= 0.77; 95% CI: 0.60-0.97; p value=0.05

and private: OR= 0.76; 95% CI: 0.65-0.91; p value=0.00 and uninsured: OR= 0.64; 95% CI: 0.48-0.88; p value=0.05]. If the patient switched insurance during the study years, they had higher odds of readmission [OR= 1.27; 95% CI: 1.09-1.48; p value=0.05] compared to those who had the same coverage for all reported hospitalizations.

The only category of poverty status that was associated with readmission was greater than equal to 50% average poverty [OR= 0.80; 95% CI: 0.65-0.99; p value=0.05]. Distance to nearest acute care hospital was also not significantly associated with readmissions.

Among the individual level factors, gender, race/ethnicity, comorbidities, and route of admission were not significant predictors of readmission. All categories of year of admission were significantly associated with higher odds of readmission compared to year 2006 [2007: OR= 0.78; 95% CI: 0.64-0.96; p value=0.02; 2008: [OR= 0.76; 95% CI: 0.62-0.94; p value=0.01; 2009: OR= 0.61; 95% CI: 0.49-0.76; p value=0.00; 2010: OR= 0.66; 95% CI: 0.53-0.84; p value=0.00; 2011: OR= 0.54; 95% CI: 0.42-0.70; p value=0.00].

If the patient switched hospitals from previous index hospitalization, they had higher odds compared to those who consistently presented at the same hospital [OR: 2.4; 95% CI: 2.01-2.90; p value<0.00]. Residents of Northern California had lower odds of having a readmission compared to those who lived in Los Angeles [OR= 0.78; 95% CI: 0.65-0.93; p value=0.00].

		30 day Readmission		
Independent Variables	OR	95% CI	p value	
Age Group				
14-17 (reference)				
18-20	1.12	0.92-1.37	0.24	
21-26	1.14	0.93-1.40	0.20	
Primary SCD Diagnosis (yes vs. no)	0.84	0.72-0.97	0.02	
Poverty Status (Percent Below FPL within Zip Code)				
0-24% (reference)				
25-49%	0.94	0.78-1.14	0.55	
≥50%	0.80	0.65-0.99	0.05	
Insurance Status				
Medicare	0.77	0.60-0.97	0.05	
Medicaid/Other Government (reference)				
Private	0.76	0.65-0.91	0.00	
Uninsured	0.64	0.48-0.88	0.05	
Distance from home to record the miles)				
Distance from nome to nearest nospital (in miles)	1.00	0.99-1.00	0.65	

 Table 17: Multi-Level Logistic Regression with Cluster Correction: Thirty Day Readmission (Tabled Continued on Next Page)
	30 day Readmission				
Independent Variables	OR	95% CI	p value		
Individual-Level Characteristics					
Gender					
Male	1.07	0.92-1.24	0.65		
Female (reference)					
Race/ethnicity					
African American (reference)					
Latino	1.25	0.93-1.68	0.42		
Other	1.00	0.72-1.40	0.16		
Common Comorbidities					
Hypertension	0.99	0.83-1.16	0.82		
Pulmonary Disease	1.09	0.92-1.37	0.24		
Fluid and Electrolyte Disorders	0.96	0.80- 1.23	0.92		
Depression	1.05	0.77-1.44	0.82		
Drug Abuse	1.17	0.89-1.58	0.22		
Route of Admission					
ED	1.00	0.86-1.17	0.79		
Non-ED or non-Admitting Hospital ED					
Year of Admission					
2006 (reference)					
2007	0.78	0.64-0.96	0.02		
2008	0.76	0.62-0.94	0.01		
2009	0.61	0.49-0.76	0.00		
2010	0.66	0.53-0.84	0.00		
2011	0.54	0.42-0.70	0.00		
Visit Number	1.07	1.05-1.09	0.00		
Insurance Switching	1.27	1.09- 1.48	0.05		
Hospital Switching	2.4	2.01-2.9	0.00		
Contextual Variables					
Place of Residence					
LA County (reference)					
Southern California	0.85	0.71-1.01	0.07		
Central California	0.72	0.49-1.04	0.08		
Northern California	0.78	0.65-0.93	0.00		
Hospital Type					
General Hospital	1.16	0.93-1.45	0.16		
Children's Hospital (reference)					

Table 17: Multi-Level Logistic Regression with Cluster Correction: Thirty Day Readmission (continued)

#### 7.4 Length of Stay

#### 7.4.1 Descriptive Analyses

Length of stay was assessed at the hospitalization level. Table 6 in section one of this chapter describes the sample that was used in the LOS analysis. The unadjusted average LOS was one day longer for 21-26 year olds (6.4 days) compared to 14-17 year olds (5.4 days). Average LOS was much shorter for uninsured patients (4.4 days) compared to Medicaid/other government (6.2 days) and Medicare patients (7.2 days). If there was change in expected insurance since the prior hospitalizations, average LOS was lower (5.7 days compared to 6.2 days). Average LOS did not differ by poverty level in zip code or residence.

#### 7.4.2 Regression Adjusted Association of Length of Stay with Age and SES:

Multivariate risk adjusted regression estimates are presented in Table 18. In the regression analysis, all age groups were associated with a statistically significant increased LOS compared to those in the 14-17 [18-20: IRR= 1.01; 95% CI: 1.01-1.03; p value=0.00 and 21-26: IRR=1.02; 95% CI: 1.01-1.03; p value=0.00]. Primary diagnosis of SCD had similar results to that of age.

All insurance categories were associated with a statically significant increase in LOS compared to Medicaid/other government except private insurance [Medicare: IRR= 1.02; 95% CI: 1.01-1.02; p value=0.00 and uninsured: IRR= 0.96; 95% CI: 0.94-0.98, p value=0.00].

Insurance switching, poverty status in zip code of residence, and distance to nearest acute care hospital were not significant predictors of LOS.

Among the individual level factors, gender was not significant factors. All categories of year had significantly decreased LOS compared to year 2006 [2007: IRR= 0.99; 95% CI: 0.98-0.999; p value=0.00; 2008: IRR= 0.98; 95% CI: 0.98-0.99; p value=0.00; 2009: OR= 0.97; 95% CI: 0.96-0.98; p value=0.00; 2010: IRR= 0.97; 95% CI: 0.96-0.97; p value=0.00; 2011: IRR= 0.96; 95% CI: 0.96-0.97; p value=0.00].

Hospital switching was not a significant predictor of LOS. Residents of Northern California had shorter LOS compared to those who lived in Los Angeles [IRR= 0.99; 95% CI: 0.99-0.99; p value=0.03].

For ease of interpretation, the results of the primary predictors of interest (age, insurance, poverty status, and distance) in regression analysis, reported as IRR, have been translated into predicted LOS in days (not shown in table). Individuals who are 21-26 years will have an average length of stay (6.4 days; 95% CI: 6.23-6.572; p value 0.00) that is more than one day longer compared to the youngest group (5.6 days; 95% CI: 5.28-5.85; p value 0.00). Age group 18-20 was not significantly different from 14-17 at 6.00 days (95% CI: 5.76-6.24). Uninsured patients had on average two to two and half days shorter length of stay (4.6 days; 95% CI: 4.22-5.12) compared to those with Medicaid/other government (6.2 days; 95% CI: 6.02-6.31; p value=0.00) , Medicare insurance (6.9 days; 95% CI: 6.46-7.32) or private

(6.11 days; 95% CI: 5.84-6.39; p value=0.00). The predicted distance to nearest

hospital (assessed by examining 10 mile intervals) was 6 miles.

		LOS	
	IRR	95% CI	p value
Age Group			
14-17 (reference)			
18-20	1.01	1.00-1.02	0.02
21-26	1.02	1.01-1.03	0.00
Primary SCD Diagnosis (yes vs. no)	1.02	1.01-1.03	0.00
Poverty Status (Percent Below FPL within Zip Code)			
0-24% (reference)			
25-49%	1.00	0.99-1.01	0.78
≥50%	1.00	0.99-1.01	0.90
Insurance Status			
Medicare	1.02	1.01-1.02	0.00
Medicaid/Other Government (reference)			
Private	1.00	0.99-1.01	0.78
Uninsured	0.96	0.94-0.98	0.00
Distance from home to nearest hospital (in miles)	1.00	0.99-1.00	0.69

# Table 18: Generalized Estimating Equation Regression Adjusted Associations: Length of Stay (Table Continued on Next Page).

	IRR	95% CI	p value
Independent Variables			
Gender			
Male	0.99	0.99-1.00	0.09
Female (reference)			
Race/ethnicity			
African American (reference)			
Latino	0.98	0.96-0.99	0.01
Other	0.98	0.97-0.99	0.01
Common Comorbidities			
Hypertension	1.04	1.03-1.04	0.00
Pulmonary Disease	1.00	0.99-1.00	0.80
Fluid and Electrolyte Disorders	1.04	1.02-1.04	0.00
Depression	1.02	1.01-1.03	0.00
Drug Abuse	0.99	0.98-1.01	0.36
Route of Admission			
ED	0.99	0.98-0.99	0.00
non-ED or non-Admitting Hospital (reference)			
Year of Admission			
2006 (reference)			
2007	0.99	0.98-0.99	0.00
2008	0.98	0.98-0.99	0.00
2009	0.97	0.96-0.98	0.00
2010	0.97	0.96-0.98	0.00
2011	0.96	0.96-0.97	0.00
Visit Number	1.0	1.00-1.00	0.00
Insurance Switching	0.99	0.98-1.00	0.10
Hospital Switching	0.99	0.98-0.99	0.00
Contextual Variables			
County of Residence			
LA County (reference)			
Southern California	1.00	1.00-1.01	0.27
Central California	0.99	0.97-1.01	0.31
Northern California	0.99	0.99-0.99	0.03
Hospital Type			
General Hospital	1.0	0.99-1.01	0.0
Children's Hospital (reference)			

# Table 18: Generalized Estimating Equation Regression Adjusted Associations: Length of Stay (continued)

#### 7.5 ED Utilization:

#### 7.5.1 Descriptive Analysis:

The ED analysis was assessed at the patient level. The majority of ED visits belonged to patients 21-26 (62%; Table 19). Over half of the population was 14-17 in January of 2006. The distribution of patient's zip code of residence was also similar to the inpatient sample. African Americans were the largest group represented (93%).

Half of the patients had Medicaid or other government source of payment. Thirty-three percent of patients had at least one insurance switch during the six year timeframe. Average distance to the nearest hospital was rescaled to 100<sup>th</sup> of a mile for model convergence. The mean distance to nearest hospital was 0.14 miles. Half the ED analytic sample resided in zip code areas of 25-50% average zip code poverty level.

	n	Percent (%)
Sickle Cell Sample		
Primary Diagnosis Visits	1,134	49
Secondary Diagnosis Visits	879	38
Hospitalizations with Matching RLN	305	13
Average count per individual (mean, SD)	12	31
Characteristics of Patients		
Adjusted Age Group on January 1, 2006		
14-17	1,112	48
18-20	515	22
21-26	687	30
Proportion of Days Patients Could		
Have Been Observed (mean/SD)	0.81	0.26
Age Group		
14-17	334	14
18-20	529	22

Table 19: Descriptive Statistics between 2006 and 2011 at Patient Level (ED Analysis (N=2,314)).

	n	Percent (%)
21-26	1,451	62
Poverty Status (Percent Below FPL within Zip Code)		
0-24%	387	17
25-49%	1,169	51
≥50%	747	32
Insurance Status at 1 <sup>st</sup> Observation		
Medicare	92	4
Medicaid/Other Government	1,106	48
Private	647	28
Uninsured	469	20
Distance from home to nearest hospital in 100th of a mile	0.14	1.48
Individual-Level Characteristics		
Male (vs. Female)	995	43
Race/ethnicity		
African American	2,082	90
Latino	78	3
Other	154	7
Year of Admission		
2006	237	10
2007	247	11
2008	275	12
2009	288	12
2010	354	15
2011	913	39
Insurance Switching	753	33
Hospital Switching	1,082	47
Contextual-Level Characteristics		
Country of Residence		
LA County	840	36
Southern California	623	37
Central California	80	4
Northern California	771	33
Hospital Type		
General Hospital	2,132	92
Children Hospital	182	8

#### 7.5.2 Regression Adjusted Association of ED visits with Age and SES:

Table 20 presents the analysis of the regression of the count of Ed visits on age, insurance status and other variables. In regression analysis, age was a significant predictor with those in the middle age group on January 1 2006, 18-20, having an expected count of ED visits 1.31 times greater than those in the youngest age group [95% CI: 1.13-1.52; p value=0.00]. Age group 21-26 had a higher expected count of ED visit [IRR = 2.27; 95% CI: 1.88-2.75; p value=0.00].

Patients with private insurance [IRR = 0.57; 95% CI: 0.49-0.68; p value=0.00] or uninsured [IRR =035; 95% CI: 0.30-0.44; p value=0.00] had a significantly lower expected count of ED visits than those with Medicaid. If the patient switch insurance they had an expected count of ED visits of 2.32 times greater than those who had the same coverage for all reported visits [95% CI: 2.03-2.61; p value=0.00].

The categories of average zip code poverty status were not significantly associated with the count of ED visits. Distance to nearest acute care hospital was also not significantly associated with ED visits.

Among the individual level factors, gender was not a significant predictor of ED visits. Those who were in the other race/ethnicity category had a significantly lower expected count [IRR=0.70; 95% CI: 0.54 -0.90; p value=0.01] compared to African Americans. All categories of year of admission were significantly associated with higher expected counts compared to year 2006 [2007: IRR=1.99; 95% CI: 1.54-2.61; p value=0.00; 2008: IRR=1.67; 95% CI: 1.26-2.18; p value=0.01; 2009: IRR=2.08; 95% CI: 1.57-2.75; p value<0.00; 2010: IRR=2.51; 95% CI: 1.93-3.29; p value=0.00; 2011: IRR=5.00; 95% CI:3.90-6.42; p value=0.00].

If the patient experienced any hospital switching, they had an expected index count of 3.60 times greater than those who consistently presented at the same hospital [95% CI: 3.16-4.10; p value=0.00]. Place of residence was not a significant predictor.

#### 7.5.3 Count of ED visits Sensitivity Analysis:

In the sensitivity analysis (Table 20), insurance status at last hospitalization was replaced with insurance status at first hospitalization to test whether the model was sensitive to which observation of insurance was included. The magnitudes of the coefficients, confidence intervals and p values in this analysis were comparable to the original analysis described above.

# Table 20: Zero-Truncated Negative Binomial Adjusted Associations: Count of ED Visits and Sensitivity Analysis (Table Continued on Next Page)

Independent Variables	(	Count of EI Observat	O Visits with tion Insurar	h Last ice	Count of ED Visits with First Observation Insurance				
	IRR	Lower	Upper	p value	IRR	Lower	Upper	p value	
Age Group at January 1 2006									
14-17 (reference)									
18-20	1.31	1.13	1.52	0.00	1.39	1.20	1.63	0.00	
21-26	2.27	1.88	2.75	0.00	2.46	2.03	3.00	0.00	
Number of Days Observed Poverty Status (Percent Below FPL within Zin Code)	1.49	1.09	2.05	0.01	1.45	1.06	1.99	0.02	
0-24% (reference)									
25-49%	1.12	0.85	1.45	0.44	1.08	0.83	1.42	0.55	
≥50%	1.25	0.90	1.70	0.17	1.22	0.89	1.68	0.22	
Insurance Status									
Medicare	0.98	0.79	1.11	0.84	0.82	0.61	1.11	0.19	
Medicaid/Other Government (reference)									
Private	0.57	0.49	0.68	0.00	0.59	0.52	0.66	0.00	
Uninsured	0.35	0.30	0.44	0.00	0.37	0.31	0.41	0.00	
Distance from home to nearest hospital in 100th of a mile	1.02	0.97	1.06	0.46	1.01	0.97	1.06	0.53	

Independent Variables	Count	of ED Visits w	ith Last Observati	on Insurance	Count of ED Visits with First Observation Insurance						
Individual-Level Characteristics	IRR	Lower	Upper	p value	IRR	Lower	Upper	p value			
Gender											
Female (reference)											
Male	1.03	0.92	1.15	0.60	1.04	0.93	1.17	0.49			
Race/ethnicity											
African American (reference)											
Latino	0.75	0.53	1.06	0.11	0.82	0.57	1.17	0.28			
Other	0.70	0.54	0.90	0.01	0.70	0.55	0.91	0.01			
Year of Admission											
2006 (reference)											
2007	1.99	1.54	2.61	0.00	1.97	1.51	2.59	0.00			
2008	1.67	1.26	2.18	0.01	1.79	1.35	2.34	0.00			
2009	2.08	1.57	2.75	0.00	2.23	1.68	2.92	0.00			
2010	2.51	1.93	3.29	0.00	2.61	1.99	3.42	0.00			
2011	5.00	3.90	6.42	0.00	5.26	4.06	6.82	0.00			
Any Insurance Switching	2.32	2.03	2.61	0.00	2.64	2.10	2.69	0.00			
Any Hospital Switching	3.60	3.16	4.10	0.00	3.71	3.25	4.22	0.00			
Contextual Variables											
County of Residence											
LA County (reference)											
Southern California	1.06	0.81	1.39	0.67	1.08	0.84	1.39	0.57			
Central California	1.17	0.72	1.92	0.52	1.21	0.73	1.97	0.75			
Northern California	1.03	0.78	1.35	0.86	1.07	0.81	1.40	0.50			

## Table 20: Zero-Truncated Negative Binomial Adjusted Associations: Count of ED Visits and Sensitivity Analysis (continued).

Effective Sample Size: 2,287

#### **CHAPTER 8: DISCUSSION**

This chapter provides the discussion of the study results. Study limitations and caveats are also discussed followed by the significance of the research. The chapter ends with a report of practice and policy implications with the final paragraphs outlining recommendations for future research.

#### 8.1 Principal Results

In this dissertation, the impact of age, insurance, poverty status and distance on hospital and emergency care utilization was examined. The findings indicate that young adults ages 18-26 with sickle cell disease may interact more with inpatient and emergency room care than children ages 14-17. Age was consistently a significant predictor of hospitalization and ED use in this study. Specifically, patients aged 21-26 had an increased count of hospitalizations, ED visits, and longer length of stay compared to 14-17 year olds. The possible reasons can be natural progression of the illness, less intensive management of the condition, shifts in insurance coverage and transitions from treatment by pediatric specialists to adult providers with less experience with child onset conditions. Age was not significantly associated with 30 day readmissions.

Insurance coverage (expected payment source in the dataset) at the time of hospitalization or ED visit was also a significant predictor of several outcomes in this study. Specifically, uninsured patients had significantly fewer index hospitalizations and ED visits and had shorter LOS. The uninsured population may face actual or perceived restrictions to care. Uninsured patients may feel the need to restrict utilization because of perceived lower quality of care or inability to pay.[66] Also, hospitals may discharge uninsured patients earlier[67].

Private insurance was also associated with fewer index hospitalizations, lower odds of a readmission, and shorter LOS. This study did not assess level of outpatient use for privately insured patients, but fewer hospitalizations compared to Medicaid beneficiaries, may be an indicator of less need. Other reasons for this finding may include greater access to primary care physicians and early detection of potential life-threatening complications that would require tertiary care (cite Freidman). In addition, Medicaid eligibility may be due to high expenditures of individuals and families for health care and spending down to qualify for Medicaid. Medicaid spending may be high compared to the uninsured because the uninsured may switch to Medicaid when their spending reaches a threshold. This merits further study in subsequent work.

Medicare was associated with higher odds of a readmission and longer LOS. Young adults with Medicare may have more severe disabling conditions that qualified them for Medicare and that place them at risk for more post-discharge complications and longer hospitalizations.

Although the timing of transitions in insurance could not be directly measured, it was inferred from changes in insurance status between hospitalizations or ED visits. Insurance switching was associated with more index hospitalizations and ED visits. Insurance switching was also associated with higher odds of a readmission. The insurance switching variable offers a limited measure of the impact of insurance transitions on hospital related care utilization. Observed switches in insurance could be related to changes in access to care services or disruptions in existing patient-provider relationships. Future research should address the need for a stronger indicator of loss of insurance to describe the relationship between loss and utilization.

Any hospital switching was included in the count of index hospitalizations and ED visits models as a signal of instability in care and lack of consistent provider source. These shifts were associated with more index hospitalizations and more ED visits. Poverty status was used as predictor of access to care, particularly specialty care that is provided in the hospital or ED. This variable was not a significant predictor of count of index hospitalization, ED visits or LOS. However, those residing in zip code areas of highest poverty (≥50%) had lower odds of a readmission. It may be that the high concentration of poor individuals in the area of residence is not a good measure of the availability of preventive and primary care services and future work should look at more direct measures of access.

Distance from home to nearest hospital was included to measure if increased travel burden restricted access to care, and this variable was not associated with any outcome. Most of the patients lived in urban settings. This lack of variation likely contributed to the nonsignificant associations.

In this study, the most common reported comorbidities were hypertension, pulmonary disease, fluid and electrolyte disorders, depression, and drug abuse. The most common conditions reported for first readmissions were pneumonia, anemia-antepartum, and anemia-delivered. These comorbid conditions are consistent with the previous literature on common complications that occur in children and adults with sickle cell disease (i.e. infections related to splenic sequestration, acute chest syndrome (ACS), and psychosocial issues).[68] Other common complications, such as renal disease, were not reported. Yet, given higher proportion of

Medicare covered patients in the age group 21-26, these young adults have a higher rate of

disabling conditions not captured by OSHPD data.

### Table 21: Summary of Main Results:

Hypothesis	Hypothesis Supported By Analyses?
Hypothesis A1: Being over the age of 20 or 18-20	Yes
will be associated with greater number of index	
hospitalizations when compared to sickle cell	
patients ages 14-17.	
Hypothesis A2: Being over the age of 20 or 18-20	No
will be associated higher odds of a readmission	
when compared to sickle cell patients ages 14-17.	
Hypothesis A4: Being over the age of 20 or 18-20	Yes
will be associated with longer length of stay per	
visit when compared to sickle cell patients ages 14-	
17.	
Hypothesis A3: Being over the age of 20 or 18-20	Yes
will be associated with greater number of ED visits	
when compared to sickle cell patients ages 14-17.	
Hypothesis B1a: Being uninsured will be	No (lower count of index
associated with greater number of index	hospitalizations)
hospitalizations compared to those insured.	
<b>Hypothesis B1b:</b> Longer distance to the nearest	No
hospital will be associated with greater number of	
index hospitalizations compared to those living	
closer to a medical facility.	
<b>Hypothesis B1c:</b> Sickle cell patients live in higher	No
poverty status areas will have greater number of	
index hospitalizations.	
Hypothesis B2a: Uninsured patients will be	No (lower odds)
associated higher odds of a readmission than those	
insured.	
Hypothesis B2b: Longer distance to the nearest	No
hospital will be associated lower odds of a	
readmission compared to those living closer to a	
medical facility.	

Hypothesis	Hypothesis Supported By Analyses?
Hypothesis B2c: Sickle cell patients live in higher	No (lower odds)
poverty status areas will be associated higher odds	
of a readmission.	
Hypothesis B3a: Uninsured patients will be	Yes
associated with shorter LOS than those insured.	
Hypothesis B3b: Longer distance to the nearest	No
hospital will be associated with longer LOS	
compared to those living closer to a medical	
facility.	
Hypothesis B3c: Sickle cell patients live in higher	No
poverty status areas will be associated with longer	
LOS.	
Hypothesis B4a: Being uninsured will be	No (lower count)
associated with greater number of ED visits	
compared to those insured.	
Hypothesis B4b: Longer distance to the nearest	No
hospital will be associated with fewer number of	
ED visits compared to those living closer to a	
medical facility.	
Hypothesis B4c: Sickle cell patients live in higher	No
poverty status areas will have greater number of ED	
visits.	

#### 8.2 Comparisons to Previous Literature

Very few studies exist to date examining the four outcomes assessed in this dissertation

for SCD. The closest comparable sickle cell studies are those published by Sobota et al. 2012,

Wolfson et al 2012 and Jan et al 2013 discussed in the literature review section in chapter one.

In this study, age was not significantly associated with 30 day readmission for SCD

patients. However, the relationship between age and 30 day readmission has been observed in

previous studies. Sobota et al., in a study of pediatric sickle cell patients in children's hospitals,

used a multivariate model accounting for repeated measures which showed that each additional year of age was associated with higher odds of a readmission (OR=1.06 (95%CI: 1.04–1.07)).

In this study, age was associated with count of ED visits. Similar results were observed in a study by Wolfson et al, who reported that a higher proportion of ED utilizers (single and multiple visits) were among adult SCD patients.[47] In addition, the authors found that adults represented a higher proportion of the uninsured populations compared to children. These descriptive findings are similar to that seen in this dissertation.

In this study, hospital type was not associated with thirty-day readmission or LOS. Previous studies have found hospital type to be a significant predictor of LOS and thirty-day readmission among children with sickle cell disease.[35] Jan et al found that longer LOS occurred in the general hospitals compared to children's hospitals, suggesting a protective factor of being treated in one setting over the other. Jan et al. found that hospital type was associated with a longer predicted length of stay by 1.4 days and higher probability of readmission in a general hospital (PP=0.09) versus a children's hospital (PP=0.08). Although the author did not explicitly examine the direct effect of age, they found that 18-25 year olds had significantly more admissions than those aged 14-17. This is consistent with the age results observed in this study.

#### 8.3 Study Limitations and Caveats

#### 8.3.1 Use of Administrative Data and Omitted Variables

Administrative data allows for the examination of the associations between predictors and dependent variables for the population of patients hospitalized with sickle cell disease in California. A limitation is that the analysis is constrained to the data elements collected by OSHPD and to several measurement issues associated from coding practices in data reported by hospitals to OSHPD.

A notable omitted item from OSHPD is any information about whether or not the patient has a primary care provider or usual source of care or any information about how often they seek and receive primary care. Previous research has shown that appropriate use of primary care may reduce hospitalization events and emergency room use by identifying any potential exacerbation in illness ahead of time. [39, 40] OSHPD does not include an indicator for patients enrolled in the CCS program. As mentioned in the introduction chapter, a majority of these patients will have Medicaid as the payer.

#### 8.3.2 Insurance Classification

Using hospital discharge data in which all insurance types are recorded is advantageous over the use of single pay claims data because it allows researchers to assess patients over time as their insurance status changes. Yet, inaccuracy in insurance coding, particularly Medicaid, weakens the findings. A study by Chattopadhyay and Bindman quantified the impact of coding inaccuracies in California's hospital discharge data on counts of hospitalization among patients with Medicaid. The authors showed that hospital discharge data overcounted 13.4% of hospitalizations for ambulatory care-sensitive conditions for non-Medicaid beneficiaries. Hospital discharge data undercounted 28.2% of hospitalizations for Medicaid beneficiaries. Furthermore, 5% of hospitalizations were coded as Medicaid even if the patients gained Medicaid coverage as a result of the hospitalization.[62] In this study, inaccuracies in coding of Medicaid and uninsured may have overestimated the association between uninsured and hospitalizations and ED visits. The results may have also overestimated the association of

insurance switching. However, the direction of bias for the results is not clear. Future work with OSHPD data should include examining the potential impact of miscoding through testing alternative way to group insurance categories such as pooling Medicaid and uninsured patients. Alternatively, future research should restrict the sample to patients close to the age that Medicaid eligibility would end to test for the impact of shifts in insurance status in a narrow age bracket where the experience is most likely to be related to miscoding.

#### 8.3.3 Hospital Type Classification

In this dissertation, hospital type was used as a proxy measure for access to pediatric specialist with experience in treating sickle cell patients in the hospital setting. General hospitals may have a large pediatric practice that is organized and marketed as an independent children's hospital. If the children's pediatric service was associated with a separate hospital identifier in OSHPD, it was included in the standalone children's hospital category. If the pediatric practice did not have a separate hospital identifier, it is included the general hospital category. General hospitals with mixed adult/children's services may underestimate the effect of expertise in treating patient with SCD in children hospitals compared to the matched expertise in the general hospitals. Therefore, the differences observed should be interpreted as the differences between standalone children's hospitals and general hospitals including children's hospitals.

#### 8.3.4 Missing Denominator

The study population only includes individuals with SCD who experience a hospitalization or ED visit within the six year data collection period. Therefore, individuals with SCD who did not experience such events are excluded from the study population. Without a

denominator of all SCD patients, it is not possible to draw inferences about population level rates of utilization. The excluded population can possibly be the largest source of selection bias as the sample is not random. As noted in chapter 7, all California residents with sickle cell disease age 14-26 was estimated to be 2,500 individual out of 5,773 or 73% of the patients observed in this dissertation. Therefore, the majority of individuals were captured in this study and the results may be generalizable a large majority of individuals with SCD residing in California during the study timeframe.

#### 8.3.5 Missing Data

One thousand twenty five observations in the PDD data set and 1,295 observations in the EDD data set were missing rln and were excluded from the analysis. In comparison to the included hospitalizations and ED visits, observations with missing data do not appear different from the rest of the study population on average zip code poverty status, year of admission and hospital type. Age group 14-17 was more represented in the excluded case compared to the included hospitalizations. Children under the age of 14-17 with missing social security numbers may have underestimated the utilization of that group. Only slight differences were observed by gender, insurance, route of admission, and place of residence. Females were slightly more represented in the excluded cases. Only African Americans were identified. Only one percent of the excluded cases were on Medicare compared to 9% of the included hospitalizations. Uninsured and private insurance was more represented in the excluded cases. Non-Ed route of admissions were more frequent in the excluded cases. The only place of residence observed among the excluded cases was the Northern California region. Perhaps regional differences in collecting social security numbers (used to produce rln) explain some of the differences

observed, although this speculation could not be confirmed. The lack of variation in race/ethnicity in excluded case is not unexpected and may be due only to the homogeneity observed in the study.

Most variables in OSHPD were fully populated with the exception of one, patient level zip code, in which only 0.46 percent of the admission sample was missing at random. Missing patient zip codes impacted variables merged from the ACS/U.S. Census and the calculated travel burden variables. Missing values only impacted the analysis for variables retained in the final models, particularly poverty status and travel from home to nearest hospital. The probability that the value was missing was completely unrelated to the value itself after adjusting for all other variables in the model allowing for a method of imputation to calculate the travel burden variable. To calculate a distance from home to nearest hospital, missing patient zip code observations were imputed by hot deck imputation.

#### 8.3.6 Attribution Errors with Diagnosis Codes

This study relies on diagnosis codes to identify cases so it is subject to risk attribution errors that lead to misclassification or misidentification of the study population. A study by Claster et al found that administrative data over reported diagnoses but under-reported procedures.[69] However, this study employed a common method for identifying a study population from administrative data. The issue is minimized by using the ICD-9-codes identified by previous researchers who have studied sickle cell disease [35, 36, 47]. Consistency with prior studies in identifying the population and their comorbid conditions aligned this study with previous publications to allow for better comparisons of results across study results.

#### 8.3.7 Severity of Illness:

This dissertation did not include a specifically defined severity of illness score to control for increasing complications as SCD patients age. Increasing severity of illness with age is a reasonable assumption as long term problems include infections (particularly to Streptococcus pneumonia), chronic leg ulcers, degeneration of the bone, blindness and chronic renal disease.[70] However, the most common comorbidities were extracted and included as covariates as proxies for individual overall health.

#### 8.4 Significance of Research

Despite the limitations outlined above, this dissertation contributes to the literature in several ways. Very few studies have examined the associations of age with patterns of hospital and emergency care utilization of SCD patients while including socio-economic and contextual characteristics. Previous studies tend to group SCD with several non-related child-onset complex chronic conditions potentially diluting or overestimating the influence of factors on increasing utilization for this unique patient population.

In addition, other studies were unable to capture utilization history that could follow patients over the course of more than one year. This dissertation examines six years of inpatient discharge and ED data, a strong advantage over one year cross-sectional studies of only one care setting. A multi-year study of both inpatient and ED data enables merging of individual patient records by patient identifiers across care settings and years. In OSPHD, visits that are initiated in the ED and subsequently result in an admission are recorded only as an inpatient visit. The ED dataset does not reflect recorded visits that resulted in hospitalization. That is, inpatient visits with an ED route of admission may be combined with the ED dataset to better determine a more accurate assessment of all ED encounters rather than those solely discharged to the home or alternative facility. Hence, compared to previous studies this dissertation was better able to determine the level of increase in hospitalizations and ED use as a function of age, while attempting to control for insurance, poverty and travel burden.

#### 8.4.1 Research Questions

This is the first study to date to test the direct effect of age on increasing admissions and readmissions, length of stay and ED visits tracking patient overtime. This provides the advantage of more fully understanding how utilization is influenced by age with this disease. Moreover, this study explored the direct impact of socio-economic status including a geographically assessed poverty indicator providing a richer understanding of patient financial resources than what administrative data typically provides.

#### 8.5 Practice and Policy Implications

From the observed results, several implications are stated below. These implications are separated into two categories, practice and policy implications.

**Practice Implications.** Either age alone or age related to insurance loss of insurance leads to greater utilization of hospital and ED care. Preventable utilization can be addressed with better quality preventive care. Routine interactions between young adults with sickle cell and clinicians and treatment team may reduce preventable hospitalizations and non-urgent ED visits. Regular office visits allows for timely education on infection prevention, pain management, what

health indicators are should be considered a medical emergency (e.g. fever as a symptom of infection), guidance on anticipating possible complications (e.g. stoke, leg ulcers, splenic sequestration and avascular necrosis of the femoral head, genetic counseling, and psychosocial assessments[71, 72]. These regular visits can also be the setting for improving self-management skills such as self-palpation of the spleen and instructions on what to do in the event of suspected enlarged spleen. Outside the clinical setting, telephone-based outreach programs, web-based applications, or smartphone applications may be used for patient self-tracking of illness.[73, 74]

Related to readmissions, more intensive management and follow-up care provides an opportunity to intervene before additional inpatient or emergency care treatment is required. Post-discharge hospital follow-up is shown to be successful in reducing unnecessary hospital care.[75] In general, when patients are monitored by condition specific providers for discharge recommendation adherence and primary care visit follow-up, readmissions may be avoided.

Another practice implication is medical counseling during adolescence to to prevent clinical exacerbations during adulthood (i.e. increases in inpatient and ED use). In a study by Lotstein et al., only 62% of children with SHCN discussed their adult health care options and upcoming changes in insurance and non-Hispanic African Americans had lower odds of having these discussions prior to adulthood[40]. Support services provide an opportunity to support adolescent sickle cell patients on changing insurance with the intention of reducing gaps in care. As stated in the introduction chapter to this dissertation, early communication between parents, patients, and providers ensures that youth with child onset conditions are knowledgeable consumers. Education regarding maintaining and obtaining health insurance and access to care after aging out for sickle cell adolescents is even more urgent due to racial and social stigmas associated with the illness. These social stigmas may serve as barriers to seeking out and

117

receiving appropriate care. Likewise, psychosocial issues such as depression and drug abuse (the most common comorbidities observed in this dissertation) plagues this group. Mood disorders and substance abuse exacerbate the need for more emergency care in the general population of young adults. Therefore, the impact of these behaviors on patients with sickle cell, a condition made worse by dehydration and exhaustion, will be dire.

**Policy Implications.** In 2010, The Affordable Care Act (ACA) changed eligibility for dependent coverage for adult children. The extension of employer-sponsor health insurance coverage only addresses the issue for a small proportion of the sickle cell population. In this study, the majority of sickle cell patients were on Medicaid or another public insurance program. Under the ACA, an even greater proportion of patients with SCD will be eligible for Medicaid. Low-income CCS young adults will now be able to receive Medicaid.

Sickle cell patients in California who age out of CCS/Medicaid may also purchase insurance via the Covered California health insurance exchange and receive subsidies based on income eligibility. However, it is yet to be determined whether any purchase insurance will provide as many condition specific (i.e. availability of specialists) and social (i.e. case management) benefits as what they currently receive in CCS. The impact of Covered California and the other changes through the ACA for young adults with complex chronic conditions who age out of CCS has yet to be researched.

#### 8.6 Future Work

This dissertation is a starting point for many additional studies on the relationship between, age, SES, hospitalization and ED use. The immediate next step would be to linking OSHPD data to Medicaid claims data and Medicaid enrollment files to better assess the role of primary care utilization and insurance respectively. At the same time, it is possible to exploit the multi-year OSHPD data by performing a longitudinal cohort analysis following the same group of patients before and after the age of 21 (the cut-off point for CCS support). In this dissertation, year of admission was included to control for time-invariant unobserved difference by year, but patients entered and exited the data. Being able to track the same patients over time will allow for more control over time-invariant unobserved individual differences. In addition, by virtue of observing the temporal order of events, the power to assess causality would be much stronger than the cross-sectional analysis.

Long-term, it would be more appropriate to shift away from administrative data towards using electronic health records that include comprehensive information including physician notes, test orders, actual test results, and prescriptions. Primary data collection would allow researchers to more closely assess the issue of health care transition than what this dissertation was able to deduce. That is, primary data would allow researchers to look at the impact of such concepts as delays in primary care, impact of follow-up after hospital discharge, and young adult self-management skills. This future research would advance our knowledge by teasing out the respective contributions of age-related disease progression, severity, insurance coverage and health care quality. APPENDIX A

### Figure 3: Correlation Matrix for variables included in model of Count of Index Hospitalizations

	А	в	с	D	E	F	G	н	I	J	к	L
<ul> <li>A. Index count</li> <li>B. Age Group in 2006</li> <li>C. Hospital Type</li> <li>D. Race/ethnicity</li> <li>E. Hospital switch</li> <li>F. Poverty status</li> <li>G. Male</li> <li>H. Insurance</li> <li>I. Payer Switch</li> <li>J. Year</li> <li>K. Place of Res.</li> <li>L. Distance</li> <li>M. Route of admis</li> <li>N. Hypertension</li> <li>O. Electolyte</li> <li>P. Pulmunary dis</li> </ul>	$\begin{array}{c} 1.0000\\ -0.0258\\ -0.0129\\ -0.0990\\ 0.4451\\ 0.0707\\ 0.0604\\ -0.2609\\ 0.3635\\ 0.4139\\ -0.0109\\ -0.0109\\ -0.0187\\ 0.1988\\ 0.0615\\ 0.1003\\ 0.0918 \end{array}$	$\begin{array}{c} 1.\ 0000\\ 0.\ 3126\\ 0.\ 0094\\ 0.\ 0955\\ 0.\ 0219\\ -0.\ 0873\\ -0.\ 0065\\ 0.\ 0889\\ -0.\ 5552\\ 0.\ 0037\\ 0.\ 0021\\ 0.\ 0972\\ 0.\ 0779\\ 0.\ 0649\\ -0.\ 0669\\ \end{array}$	1.0000 -0.0099 0.1185 -0.0030 0.0638 0.0754 -0.1072 -0.0272 0.0218 0.1072 -0.0272 0.0218 0.1072 -0.0051 0.0532 -0.1179	1.0000 -0.1104 -0.0465 -0.0586 0.0621 -0.0922 -0.0575 0.0532 0.0033 -0.1208 0.0012 -0.0123 -0.0123	1.0000 0.0787 0.0366 -0.1515 0.4041 0.2415 -0.0549 0.0384 0.1393 0.0377 0.1054 -0.0031	1.0000 -0.0307 -0.1107 -0.0039 0.0313 -0.1863 -0.0092 0.0174 0.0182 0.0092 -0.0059	1.0000 0.0070 0.0406 0.0434 -0.0346 0.0248 0.1953 -0.0708 0.0177 0.0235	1.0000 -0.1018 -0.0935 -0.0034 0.0247 0.0234 -0.0301 -0.0313 -0.0775	1.0000 0.2036 -0.0066 0.0213 0.1401 0.0190 0.0591 -0.0003	1.0000 0.0044 -0.0050 0.0557 0.0454 0.0378 0.0483	1.0000 0.0249 0.0008 0.0796 0.0014 0.0979	1.0000 0.0354 -0.0120 -0.0191 -0.0014
M N	0	Р										
M.   1.0000 N.   -0.0350 1.0000 O.   0.1288 0.3728 P.   0.0567 0.4689	1.0000 0.0566 1	. 0000	-									

Correlation Matrix for Count of Iniital and Index Hospitalizations Model Unit of Analsys (n=1,825)

## Figure 4: Correlation Matrix variables included in model of 30 Day Readmission Model

Correlation Matrix for 30 day Readmission Model Unit of Analsys (n=8,275)

		А	В	С	D	E	F	G	н	I	J	К	L	М	N
A. 30 day rea B. Age group C. Poverty st D. Visit numb E. Primary Sc F. Male G. Race/ethni H. Insurance I. Payer Swit J. Hospital T K. Hospital T K. Hospital S L. Year M. Place of R N. Distance O. Route of a P. Depression Q. Drug R. Hypertensi S. Electolyte T. Pulmunary	dmit   er d dx   city   ype witch   es.   dmis   dis   P	1.0000 0.0880 0.0046 0.1412 0.0116 0.0170 -0.0155 -0.0673 0.0967 0.0488 0.1673 -0.0029 -0.0396 0.0057 0.057 0.0508 0.0374 0.0354 0.0177 0.0061	1.0000 0.0470 0.2518 -0.0204 -0.0189 -0.0164 -0.0884 0.1889 0.3495 0.2670 0.0495 -0.0206 0.0122 0.2265 0.02265 0.02265 0.02265 0.02265 0.02265 0.02265 0.02263 0.0730 0.0963 0.0730 0.0920 -0.0843 R	1.0000 0.0611 0.0059 0.0072 -0.0232 -0.1017 -0.0799 0.0006 0.0513 0.0211 -0.1963 -0.0291 0.0494 -0.0008 0.0026 -0.0331 0.0085 -0.0243 S	1.0000 0.1861 0.0279 -0.0677 -0.2296 0.1835 0.0597 0.2218 0.4663 -0.0010 -0.0249 0.1599 0.0692 0.0670 0.0814 0.0207 0.0629 T	1.0000 0.1516 -0.1266 -0.0347 0.0950 -0.0110 0.0105 -0.0287 0.0155 0.2586 0.0056 -0.0443 -0.1260 -0.0455 -0.0146	1.0000 -0.0187 0.0280 -0.0085 -0.0102 0.0117 -0.0065 -0.0442 0.0133 0.1260 -0.0212 0.0323 -0.0106 0.0061 0.0222	1.0000 0.0622 -0.0576 0.0285 -0.0034 -0.0153 -0.0066 -0.0092 -0.0217 -0.0037 -0.0037 -0.0052 -0.0280	1.0000 -0.0141 0.0502 -0.1210 -0.0425 -0.0427 -0.0425 -0.0248 -0.0222 -0.0646 -0.0228 -0.0671	1.0000 0.0985 0.2863 0.0481 0.0137 0.0246 0.1197 0.0275 0.0139 -0.0074 0.0114 -0.0386	1.0000 0.1145 -0.0223 -0.0811 0.0139 0.1375 -0.0028 0.0521 -0.0462 0.0600 -0.1444	1.0000 -0.0719 -0.0498 0.0130 0.1505 0.0591 0.0416 0.0151 0.0432 -0.0521	1.0000 -0.0000 -0.0177 0.0523 -0.0105 0.0378 0.0769 0.0460 0.0691	1.0000 0.0108 -0.0052 -0.0324 0.0300 0.0717 -0.0001 0.0834	1.0000 0.0172 -0.0078 0.0066 -0.0040 -0.0041 -0.0030
0.   1.0 P.   0.0 Q.   0.0 R.   0.0 5.   0.0 T.   -0.0	000 304 1.0 341 0.0 038 0.2 938 0.0 065 0.0	0000 951 1.00 201 0.24 9286 0.03 9583 0.01	00 92 1.00 00 0.37 75 0.52	00 91 1.00 96 0.04	00 25 1.00	000									

## Figure 5: Correlation Matrix variables included in model of Length of Stay Model

Correlation Matrix for Full PDD Sample (N=13,335)													
		А	В	с	D	E	F	G	н	I	J	к	L
A. Los B. Age gro C. Race/et D. Hospita E. Hospita F. Primary G. Visit n H. Poverty I. Male J. Insuran K. Payer S L. Year M. Place o N. Distanc O. Route o P. Depress Q. Drug R. Hyperte S. Electol T. Pulmuna	up hnicity l Type l switch Scd dx umber status ce witch f Res. e f admis f admis yte ry dis.	$\begin{array}{c} 1.000\\ 0.051\\ -0.029\\ 0.006\\ -0.018\\ 0.031\\ 0.054\\ 0.007\\ -0.015\\ -0.058\\ -0.019\\ -0.036\\ -0.020\\ -0.036\\ -0.020\\ -0.004\\ 0.004\\ 0.074\\ 0.029\\ 0.133\\ 0.130\\ 0.049\end{array}$	$\begin{array}{c} & & & & \\ & & &$	$\begin{array}{c} 1.0000\\ -0.0087\\ -0.0395\\ -0.1068\\ -0.0652\\ -0.0469\\ -0.0200\\ 0.0760\\ -0.0188\\ 0.0149\\ -0.0240\\ -0.0010\\ -0.0735\\ 0.0069\\ -0.0248\\ 0.0118\\ -0.0030\\ -0.0165\end{array}$	$\begin{array}{c} 1.0000\\ 0.1080\\ 0.0008\\ 0.0784\\ 0.0026\\ 0.0009\\ 0.0434\\ 0.0651\\ -0.0037\\ -0.0722\\ 0.0310\\ 0.1280\\ -0.0294\\ 0.0365\\ -0.0544\\ 0.0508\\ -0.1455\end{array}$	1.0000 -0.0293 0.1463 0.0106 -0.0239 -0.0511 0.0728 0.0471 -0.0317 -0.0260 0.0039 0.0292 0.0668 0.0390 0.0507 -0.0201	1.0000 0.1322 0.0301 0.1634 -0.0304 0.0312 0.0075 -0.0602 0.2500 -0.0079 -0.0515 -0.1335 -0.0644 -0.0219	1.0000 0.1290 0.0426 -0.2080 0.0055 0.3399 -0.0888 -0.0458 0.1552 0.0912 0.1758 0.1114 0.0372 0.0577	1.0000 0.0424 -0.1157 -0.0569 0.0390 -0.1955 -0.0296 0.0491 -0.0147 -0.0144 -0.0264 0.0088 -0.0282	1.0000 0.0356 -0.0023 -0.028 -0.0684 0.1069 -0.0466 0.0336 -0.0193 -0.0134 0.0028	1.0000 0.0910 -0.0532 -0.0320 0.0604 -0.0289 -0.0049 -0.0128 -0.0574 -0.0190 -0.0479	1.0000 -0.0086 0.0124 -0.0074 0.0449 -0.0050 -0.0077 -0.0266 -0.0060 -0.0356	1.0000 0.0172 0.0002 0.0589 -0.0203 0.0359 0.0806 0.0584 0.0743
	М	N	0	Р	Q	R	S	т					
M. N. O. P. Q. R. S. T.	1.0000 -0.1368 -0.0119 -0.0291 0.0160 0.0579 0.0089 0.0823	1.0000 0.0259 -0.0096 -0.0122 -0.0097 0.0075 -0.0038	1.0000 0.0373 0.0540 0.0091 0.0819 -0.0044	1.0000 0.0874 0.2488 0.0305 0.0527	1.0000 0.2839 1 0.0576 ( 0.0471 (	L.0000 D.3757 D.5007	1.0000 0.0463	1.0000					

### Figure 6: Correlation Matrix variables included in model of ED Visits Model

Correlation Matrix for Count of ED visits Model Unit of Analsys (n=2,314)

	А	В	С	D	E	F	G	н	I	J	к	L
A. Count of Ed visits B. Age Group C. Race/ethnicity D. Hospital Type E. Hospital switch F. Poverty status G. Male H. Insurance I. Payer Switch J. Year K. Place of Res. L. Distance	1.0000 0.1511 -0.0572 -0.0186 0.1329 0.0604 0.0186 -0.1575 -0.0303 0.1562 0.0074 0.0088	1.0000 -0.0356 0.2526 0.0936 0.0208 -0.0576 0.0525 0.0409 -0.1028 -0.0351 0.0075	1.0000 -0.0363 -0.0432 -0.0178 0.0050 0.0481 0.0035 -0.0637 0.0046 -0.0063	1.0000 0.0505 -0.0000 -0.0311 0.0951 0.0305 -0.0748 -0.0684 -0.0208	1.0000 0.0103 -0.0319 -0.0237 0.2529 0.1014 -0.0025 0.0597	1.0000 -0.0204 -0.0349 0.0023 0.0547 -0.1559 -0.0194	1.0000 0.0153 -0.0153 0.0264 -0.0450 0.0006	1.0000 0.0754 -0.1159 -0.0120 0.0560	1.0000 0.0328 0.0178 0.0215	1.0000 -0.0343 -0.0292	1.0000 0.0082	1.0000

Figure 11: NLMIXED Syntax for Count Models

```
proc nlmixed data=data_file;
xb = b0 + b1*X1 + b2*X2
mu = exp(xb + e);
m = 1/alpha;
ll = lgamma(y+m)-lgamma(y+1)-lgamma(m) +
y*log(alpha*mu)-(y+m)*log(1+alpha*mu)
- log(1 -( 1 + alpha*mu)**(-m));
model y ~ general(ll);
random e ~ normal(0,exp(sd*sd)) subject=cluserid;
run;
```

APPENDIX B

LITERATURE REVIEW SUMMARY							
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique		
Wolfson, 2012	Sickle Cell Disease in California: Sociodemographic Predictors of Emergency Department Utilization	Data Source: 2007 OSHPD data Analysis: Multivariate regression	2,920 California patients with SCD made 16,364 ED visits.	Adults $\geq 21$ years of age had higher ED visit rates than children and were more likely to both be in the highest tier of users and visit multiple facilities. Patients living further from a self-identified provider of comprehensive SCD care had higher rates of ED visits and a lower likelihood of hospitalization from the ED. Publicly insured patients had higher rates of ED visits and were more likely to be in the highest tier of users than were the privately insured or uninsured.	Did not look at individuals over time		
Wonson, 2012	Thirty-day readmission rates following hospitalization for pediatric sickle cell crisis at freestanding	<b>Data Source:</b> Pediatric Health Information System database	12, 104 sickle cell hospitalizations	In sample of hospitals, 17% of hospitalizations for scd resulted in readmission within 30 days,	Included demographic factors as controls		
Sobota, 2012	children's hospitals: risk factors and hospital variation.	Analysis: logistic regression/GEE/ adjusting for case- mix	at 33 freestanding children's hospitals	Older patients, those treated with steroids, and admitted for pain were more likely to be readmitted.	but did not report difference between SES groups		

LITERATURE REVIEW SUMMARY								
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique			
Jan, 2013	Association of Hospital and Provider Types on Sickle Cell Disease Outcomes	Data Source: 2007-2009 Premier Database Analysis: logistic regression and zero truncated negative binomial regression	1476 patients ages 16 to 25 years with 2299 admissions with SCD and ACS discharged from 256 US hospitals	General hospitals were associated with higher intubation rates and longer LOS compared with children's hospitals. There was no difference by hospital type or provider specialty in PP of simple or exchange transfusion, or 30-day readmission.				
Frei-Jones, 2009	Multi-modal intervention and prospective implementation of standardize sickle cell pain admission orders reduces 30- day readmission rate	Data Source: Hospital medical records Analysis: Chi square and Fisher's Exact Test; Student's t- test. AMann– Whitney U test	89 admissions, in 68 individuals in intervention period; 85 admissions in 56 individuals during the control period	A multi-modal intervention was successful in decreasing 30-day hospital readmission rate for children with SCD and pain. Provider education was the most important component of the multimodal intervention.	Did not adjust for multiple visits per patient that might bias the results by including potentially more severe cases			

LITERATURE REVIEW SUMMARY								
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique			
Frei-Jones, 2009	Risk Factors for Hospital Readmission Within 30 Days: A New Quality Measure for Children With Sickle Cell Disease	Data Source: Hospital medical records Analysis: retrospective cohort study	30 cases and 70 controls	Greatest risk factor for readmission was no outpatient hematology follow-up within 30 days of discharge (OR 7.7, 95% CI 2.4–24.4). A diagnosis of asthma was also a risk factor for readmission (OR 2.9, 95% CI 1.2–7.3). Patients who required supplemental oxygen to maintain saturations in the normal range and were on room air for 24 hr at discharge	Potential autocorrelation between outcome and disease severity score defined as $\geq 3$ admission in a 1 year period			
Viner, R, 1999	Transition from pediatric to adult care. Bridging the gaps or passing the buck?	<b>Data Source:</b> N/A <b>Analysis:</b> Review of Best-Practices for Transition	N/A	Transition in mid-adolescence should be avoided. Transition programmers are necessary even when paediatric and adult services are in the same hospital because geographical proximity frequently does not translate into a close professional relationship. Table 1 gives best-practice recommendations				
LITERATURE REVIEW SUMMARY								
----------------------------	--------------------	-------------------------	---------------------------	---	---------------------	--	--	
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique			
				Internists clearly stated the need for better training in congenital				
				and childhood-onset conditions,	selection bias from			
				training of more adult	53% response rate.			
				family involvement. They also	providers possibly			
		Data Source: 2-		identified concerns about	return survey or			
	Transition From	Stage Mail Survey		patients' psychosocial issues and	the providers who			
	Pediatric to Adult	Analysis:	241 internal	maturity, as well as financial	are most willing to			
	Care: Internists'	Kruskal-Wallis	medicine	support to care for patients with	learn about			
Nadja G Peter/2009	Perspectives.	Test	providers	complex conditions.	transition			

LITERATURE REVIEW SUMMARY						
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique	
Committee on Children with Disabilities/2000	The Role of the Pediatrician in Transitioning Children and Adolescents With Developmental Disabilities and Chronic Illnesses From School to Work or College. Pediatrics	<b>Data Source:</b> n/a <b>Analysis:</b> n/a	N/A	Abstract: The role of the pediatrician in transitioning children with disabilities and chronic illnesses from school to work or college is to provide anticipatory guidance and to promote self-advocacy and self-determination. Knowledge of the provisions of the key federal laws affecting vocational education is essential for the pediatrician's successful advocacy for patients.		
Goodman, D.M., et al./2011	Adults With Chronic Health Conditions Originating in Childhood: Inpatient Experience in Children's Hospitals	Data Source: Data from January 1, 1999, to December 31, 2008, from patients hospitalized at 30 academic children's hospitals Analysis:	Including growth rates according to age group (pediatric: aged 18 years; transitional: aged 18 –21 years; or adult: aged 21 years) and disease.	The number of unique patients, admissions, patient-days, and charges increased in all age groups over the study period and are projected to continue to increase.		

LITERATURE REVIEW SUMMARY						
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique	
Knopf, J.M., et al/2005	Health Care Transition: Youth, Family, and Provider Perspectives.	Data Source: Survey Analysis: logistic regression	82 adolescents seen at one of four paediatric chronic illness subspecialty clinics and 62 of their parents.	nearly equal percentages of adolescents (37%) and parents (36%) preferred shared decision making. Overall, the largest proportion of adolescents (46%) and parents (53%) preferred passive decision making compared to active or shared decision making.		
Viner, R.M./2008	Transition of care from paediatric to adult services: one part of improved health services for adolescents	<b>Data Source:</b> N/A <b>Analysis:</b> Report of Best-Practices for Transition	N/A	three elements must be pursued with vigour. 1) a cultural shift in NHS staff attitudes and training is required. 2) systems must change to ensure that all paediatric chronic illness and disability services have effective transition programmes in place. 3) young patients need to be trained and empowered to allow them to be an effective partner in their own transition.		

LITERATURE REVIEW SUMMARY								
Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique				
The Transition to Adult Health Care for Youth With Special Health Care Needs: Do Racial and Ethnic Disparities Exist?	Data Source: N/A Analysis: Review	reviewed research on transition preparation and outcomes for YSHCN to find evidence of racial and ethnic disparities.	The results of this review indicate that few YSHCN are receiving adequate transition preparation, and some evidence indicates that this situation is worse for racial and ethnic minorities.					
Transition to Adult Health Care for Adolescents and Young Adults with Chronic Conditions: Position Paper of the Society for Adolescent Medcine. Journal of Adolescent Health	Data Source: N/A	N/A	Review of principle sof succesful transition: 1) chronological age and developmental appropriate 2) address common concerns of young people 3) support increasing autonomu 4) individualized 5) designated professional serves as transition					
	Title The Transition to Adult Health Care for Youth With Special Health Care Needs: Do Racial and Ethnic Disparities Exist? Transition to Adult Health Care for Adolescents and Young Adults with Chronic Conditions: Position Paper of the Society for Adolescent Medcine. Journal of Adolescent Health	W SUMMARYTitleStudy Design/MethodsThe Transition to Adult Health Care for Youth With Special Health Care Needs: Do Racial and Ethnic Disparities Exist?Data Source: N/A Analysis: ReviewTransition to Adult Health Care for Adolescents and Young Adults with Chronic Conditions: Position Paper of the Society for AdolescentData Source: N/A Analysis: ReviewData Source: N/A Analysis: ReviewData Source: N/A Analysis: Review	W SUMMARYTitleStudy Design/MethodsSample and Sample SizeThe Transition to Adult Health Care for Youth With Special Health Care Needs: Do Racial and Ethnic Disparities Exist?reviewed research on transition ySHCN to find evidence of racial and ethnic disparities.Transition to Adult Health Care for Adolescents and Young Adults with ChronicData Source: N/A Analysis: ReviewTransition Paper of the Society for AdolescentData Source: N/A HealthData Source: N/A HealthNata Source: N/A Analysis: Review	SW SUMMARYTitleStudy Design/MethodsSample and Sample SizeBrief Summary of FindingsThe Transition to Adult Health Care for Youth With Special Health Care Needs: Do Racial and Ethnic Disparities Exist?reviewed research on transition YSHCN to find evidence of racial and ethnic disparities.The results of this review indicate that few YSHCN are receiving adequate transition preparation, and some evidence evidence of racial and ethnic disparities.Transition to Adult Health Care for Adolescents and Young Adults with ChronicData Source: N/A Analysis: ReviewReview of principle sof succesful transition: 1) chronological age and developmental appropriate 2) address common concerns of young people 3) support individualized 5) designated professional serves as transitionData Source: N/A HealthN/Aspecialist				

LITERATURE REVIEW SUMMARY						
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique	
McDonagh, J.E.,2005	Growing up and moving on: Transition from pediatric to adult care	Data Source: N/A Analysis: Review	N/A	Abstract: This paper is to present the philosophy of transition and an evidence-based approach to transitional care in terms of the need for it, proposed models of care and the evidence of the benefits of transitional care programs. Examples of some key clinical aspects of transitional care including communication skills, parenting, self-advocacy, vocation will be presented.		
White, P.H., 2002	Access to Health Care: Health Insurance Considerations for Young Adults With Special Health Care Needs/Disabilities	Data Source: N/A Analysis: Review	N/A	The article outlines what steps could be taken by associations and the health policy, advocacy, and governmental communities to improve the complex system of health insurance options that young adults with special health care needs/disabilities face as they move from pediatric to adult health insurance systems.		

LITERATURE REVIEW SUMMARY							
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique		
Gurvitz, M.Z., et al., 2007	Changes in Hospitalization Patterns Among Patients With Congenital Heart Disease During the Transition From Adolescence to Adulthood	Data Source: 2000 to 2003 California hospital discharge database Analysis:	9,017 hospitalizations at 368 hospitals				
Okumura M. et al	Inpatient health care use among adult survivors of chronic childhood illnesses in the	<b>Data Source:</b> 2002 Nationwide Inpatient Sample <b>Analysis:</b> case- mix-adjusted, sample-weighted	hospitalizations for persons aged 18 years or older with a diagnosis of complex congenital heart disease, cystic fibrosis, sickle cell disease, or	Abstract: The vast majority of persons who have survived to adulthood with complex congenital heart disease, cystic fibrosis, spina bifida, or sickle cell disease are hospitalized in hospitals that predominantly care for adults, where charges for care appear to be lower than in pediatric hospitals.	observational study; didn't look at patient change		
2006	united states	regression analysis	spina bifida	pediatric nospitais.	in LOS overtime		

LITERATURE REVIEW SUMMARY						
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique	
Adams, S.H., et al. 2007	Health Insurance Across Vulnerable Ages: Patterns and Disparities From Adolescence to the Early 30s.	Data Source: 2002 and 2003 National Health Interview Survey Analysis: logistic regression	ages 13-32; N = 48,827	Insurance patterns follow a U- shaped curve across the age categories. Rates are highest at ages 13 to 14, lowest at ages 23 to 24, and then increase gradually. In bivariate analyses, black and Hispanic groups had lower coverage rates than the white group, and the low- and middle-income groups had lower rates than the high-income group.	data are cross- sectional, not longitudinal	
Feinberg, E., et al. 2002	Family Income and the Impact of a Children's Health Insurance Program on Reported Need for Health Services and Unmet Health Need.	Data Source: surveyed parents or guardians of children who were enrolled in a state- sponsored health insurance program (Massachusetts Children's Medical Security Plan [CMSP]) Analysis:	996 children	positive impact of providing health insurance coverage to children regardless of income	Massachusetts stands out among states as a leader in child health; may not be representative of other states	

LITERATURE REVIEW SUMMARY							
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique		
The Child & Adolescent Health Measurement Initiative, 2012	Data Resouce Center for Child & Adolescent Health A project of the Child and Adolescent Health Measurement Initiative	www.childhealthdat	N/A	N/A	N/A		
				Abstract: The concept of self- management is based on the notion that it will improve wellbeing and strengthen self- determination and participation in health care, while reducing			
	Self-management			health care utilization and health costs. Increasing self- management is a desirable goal for the 15%-20% of children and adolescents who have a significant ongoing health care			
	in adolescents with chronic illness. What does it mean			need related to a chronic health condition. Parent and Doctors should seek to optimize their			
Sawyer, S.M. and R.A. Aroni, 2005	and how can it be achieved?	<b>Data Source:</b> N/A <b>Analysis:</b> Review	N/A	child or patients independent role in health care interactions.	N/A		

LITERATURE REVIEW SUMMARY							
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique		
	Impact of Asthma Self-management	<b>Data Source:</b> Two Hospital Databases	298 children (attended, n = 126; did not attend, n = 172) admitted to a New England children's hospital in 2006 with a primary diagnosis of asthma; parents attended a short, group-based, inpatient asthma self-	"Results support modifying the short, group-based inpatient asthma self-management			
	on Pediatric	Analysis: A	management education	education program examined in this study to include additional			
Tolomeo, C., C.	Department Visits	comparative,	program and	self-efficacy building strategies			
Savrin, and M.M.	and	descriptive study	parents did not	that promote enhanced self-	Convenience		
Heinzer, 2010	Hospitalizations	Chi-Square	attend.	management"	sample		

LITERATURE REVIEW SUMMARY							
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique		
Callahan, S.T., G.B. Hickson, and W.O. Cooper, 2007	Health Care Access of Hispanic Young Adults in the United States	Data Source: National Health Interview Survey (NHIS) from 1999-2002 Analysis: Descriptive	5189 Hispanic and 13,214 white young adults (19-29 years old)	Young adults of Central/South American, Mexican, or Puerto Rican origins were more likely than whites to be uninsured ( $28\%$ - $64\%$ vs. $22\%$ ; p < .01) and this was especially true for noncitizens. Central/South American and Mexican young adults without U.S. citizenship were most likely to be uninsured ( $63\%$ and $73\%$ , respectively). The majority of noncitizens also lacked a usual source of care and had no health professional contact in the prior year	omitted variable: differences in health status for the subgroups, perceived need for care, preferred language and measures of acculturation		
Laditka, J.N., S.B. Laditka, and M.P. Mastanduno/2003	Hospital utilization for ambulatory care sensitive conditions: health outcome disparities associated with race and ethnicity.	Data Source: National Health Interview Survey (NHIS) from 1999-2002 Analysis: Adjusted relative rates	total weighted sample size: 184,686,064.	African Americans and Hispanics have significantly higher rates of ACS hospitalization than non- Hispanic whites. This result applies to women and men, and both age groups studied.	didn't examine heterogeneity within race/ethnic groups		

LITERATURE REVIEW SUMMARY							
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique		
Oster, A. and A.B. Bindman/2003	Emergency Department Visits for Ambulatory Care Sensitive Conditions: Insights into Preventable Hospitalizations.	Data Source: The National Hospital Ambulatory Care Survey; The National Health Interview Survey Analysis: Logistic Regression	2,239	The disproportionate ED utilization for chronic ACS conditions by African Americans and Medicaid patients does not appear to be explained by either differences in disease prevalence or disease severity.	limited information on patients' actual ambulatory care use		
Berry Jg, H.D.E.K.D.Z. and et al./2011	Hospital utilization and characteristics of patients experiencing recurrent readmissions within children's hospitals.	Data Source: 37 US children's hospitals in 2003 with follow-up through 2008. Analysis: Retrospective cohort analysis	317,643 patients ( $n = 579,504$ admissions) admitted to	Among a group of pediatric hospitals, 18.8% of admissions and 23.2% of inpatient charges were accounted for by the 2.9% of patients with frequent recurrent admissions. Many of these patients were re- hospitalized recurrently for a problem in the same organ system	limitations related to all inpatient administrative data		
Begley, C., et al./2006	Emergency Room Use and Access to Primary Care: Evidence From Houston, Texas	<b>Data Source:</b> <b>Analysis:</b> Retrospective cohort analysis		Primary care-related ED visits were found to be weakly correlated with the IMU and strongly correlated with the rate of uninsurance and poverty.			

LITERATURE REVIEW SUMMARY						
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique	
Want, HY., et al./2007	The use of Charlson comorbidity index for patients revisiting the emergency department within 72 hours.	Data Source: Non-trauma patients aged above 17 years old who revisited an urban ED within 72 hours during January of 2004 Analysis: retrospective observational study	168 enrolled patients	Revisiting patients with high CCIs (> or = 2) had a higher admission rate (67.3% vs. 22.7%; p < 0.001) and an increased adjusted odds ratio of admission (odds ratio (OR) 2.06; 95% confidence interval (CI) 1.14-3.75) than low CCI patients	short study period	
Brousseen D.C. of	Acute Care Utilization and Rehospitalizations	Data Source: 2005 and 2006 Healthcare Cost and Utilization Project (HCUP) State Inpatient Databases and State Emergency Department Databases Analysis: Retrospective achort of sigkla	21,112 patients with sickle cell- related treat- and-release ED visits or	Among patients with sickle cell disease, acute care encounters and re-hospitalizations were frequent, particularly for 18- to 20 year olds	Descriptive Study	
al./ 2010	Disease.	cell	hospitalizations	ou-year-olds.	Only	

LITERATURE REVIEW SUMMARY						
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique	
	Validation of the	Data Source: 49 hospitals Analysis: predictive	Validation of the Potentially			
	Potentially Avoidable Hospital	performance of risk adjustment methods:	Avoidable Hospital Readmission			
	Readmission Rate as a Routine Indicator of the	predictive value of the screening of potentially	Rate as a Routine Indicator of the	Adjusted rates of potentially avoidable readmissions are scientifically sound enough to	mutiple condition	
Halfon, P., et al./2006	Care.	readmissions.	Hospital Care.	hospital quality surveillance.	mix adjust	

LITERATURE REVIEW SUMMARY						
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique	
		Data Source: Medicare UB-82 claims data Analysis: .Condition- specific models to predict readmission risk; models then were used to calculate readmission risk		"In each of the 12 clinical conditions studied, readmission rates of cases that received poor quality care were essentially the same as those whose care was judged acceptable. This was true		
		probabilities for patients whose		both for readmission rates that were adjusted for patients'		
	Does Risk-	medical records		demographic and clinical		
	Adjusted	had been reviewed		characteristics, and for		
	Readmission Rate	tor quality of care		unadjusted rates, such as those		
	Provide Valid	by a Medicare		typically displayed in hospital	<b>T</b> 11 - 1	
	Information on	peer review	** 1	report cards."	Full article	
Thomas, J.W./1996	Hospital Quality?	organization	Unknown		unavailable	

LITERATURE REVIEW SUMMARY						
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique	
		Data Source:CTM-15				
		questionnaire Analysis:				
		Cronbach's alpha and construct				
		with T-test or				
		correlation;	A total of 414			
		Exploratory factor analysis was	(proxy: 96.1%) and 165 (proxy:	The care transition measure is a valid and reliable measure for	limit	
	Validation of the care transition	performed to	84.8%) subjects completed the	quality of care transition in Singapore. Moreover, the care	generalisability include relatively	
	measure in multi-	dimensions of	interviews in	transition measure can be	low response rate,	
Bakshi, A., et al./2012	Asia in Singapore.	CTM-15.	English and Chinese	simpler response scale.	all patients aged 50 years or older	

LITERATURE REVIEW SUMMARY						
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique	
	The impact of	<b>Data Source:</b> An in-person interview containing several standardized instruments	210 family respondents	transient situations such as homeless episodes, foster care placement, and living in more than one location in the same 1- year period will contribute to loss in Medicaid coverage; Findings indicated that children who lost Medicaid coverage, compared to others, had significantly fewer preventive care health visits. There were no differences in emergency room visits. Transient situations did not appear to influence preventive or emergency room care. In addition, the change into a managed-care delivery system also increased loss of coverage	generalizability:	
	insurance lapse	Analysis:	were recruited	Loss of coverage may be a	selected from only	
Zlotnick C and I	among low-	Retrospective	over a 1-year	harrier to preventive care	one	
Soman/2004	income children.	cohort	period.	services.	site	

LITERATURE REVIEW SUMMARY						
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique	
Thomas, J., K. Guire, and G. Horvat/1997	Is patient length of stay related to quality of care?	Data Source: hospital claims records from Medicare beneficiaries in provided by Michigan Peer Review Organization, Inc. (MPRO) Michigan Analysis: Unknown	Unknown	This article shows that in every one of the 13 clinical conditions examined, cases that received poor quality care had significantly longer risk-adjusted LOSs than cases whose care was of acceptable quality.	Full article unavailable	
Roby, D.H., et al./2010	Impact of Patient- Centered Medical Home Assignment on Emergency Room Visits Among Uninsured Patients in a County Health System	Data Source: claims data from the population enrolled in the MSI program in Orange County, California, between September 2006 and March 2009 Analysis:	2,708 individuals who had MSI claims as far back as September 2006	Medical Services Initiative enrollees who were assigned to a medical home for longer time periods were less likely to have any emergency room (ER) visits or multiple ER visits. Switching medical homes three or more times was associated with enrollees being more likely to have any ER visits or multiple ER visits.	The medical home discussed in the article was implemented in a relatively short period time to see realistic changes	

LITERATURE REVIEW SUMMARY						
Author/Publication Year	Title	Study Design/Methods	Sample and Sample Size	Brief Summary of Findings	Short Critique	
Ansell, D., et al./2002	Primary Care Access Decreases Nonurgent Hospital Visits for Indigent Diabetics.	Data Source: prospectively with baseline and 3-, 6- , and 12-month surveys; baseline and 6-month hemoglobin A1Cs; and chart reviews Analysis:	218 adults with diabetes mellitus	Those with a primary care visit within 3 months of enrollment received more of the four diabetes services during the study year than those without. Access to primary care was associated with decreased utilization of nonurgent episodic care services and better quality of diabetes care.	Full article unavailable	
Ellison, A.M. and H. Bauchner/2007	Socioeconomic Status and Length of Hospital Stay in Children With Vaso-Occlusive Crises of Sickle Cell Disease	Data Source: Healthcare Cost and Utilization Project Kid Inpatient Database 2000 Analysis: Negative binomial regression models using generalized estimating equations (GEE)	19,174 discharges (aged 1-20 years),	Socioeconomic status as measured by income was not associated with length of stay (incidence rate ratio (highest versus lowest category) = 1.04 (95% CI: 0.98, 1.11)).	only two measures of SES	

## REFERENCES

- 1. Goodman, D.M., et al., *Adult Survivors of Pediatric Illness: The Impact on Pediatric Hospitals*. Pediatrics, 2002. **110**(3): p. 583-589.
- 2. Scal, P. and M. Ireland, *Addressing Transition to Adult Health Care for Adolescents With Special Health Care Needs*. Pediatrics, 2005. **115**(6): p. 1607-1612.
- 3. Viner, R., *Transition from pediatric to adult care. Bridging the gaps or passing the buck?* Arch Dis Child, 1999. **81**: p. 271-275.
- 4. Peter, N.G., et al., *Transition From Pediatric to Adult Care: Internists' Perspectives*. Pediatrics, 2009. **123**(2): p. 417-423.
- 5. Committee on Children with Disabilities, *The Role of the Pediatrician in Transitioning Children and Adolescents With Developmental Disabilities and Chronic Illnesses From School to Work or College*. Pediatrics, 2000. **106**(4): p. 854.
- 6. Goodman, D.M., et al., *Adults With Chronic Health Conditions Originating in Childhood: Inpatient Experience in Children's Hospitals.* Pediatrics, 2011. **128**(1): p. 5-13.
- 7. Knopf, J.M., et al., *Views of treatment decision making from adolescents with chronic illnesses and their parents: a pilot study.* Health Expectations, 2008. **11**(4): p. 343-354.
- 8. American Academy of Pediatrics, et al., *Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home*. Pediatrics, 2011. **128**(1): p. 182-200.
- 9. McDonagh, J.E., *Growing up and moving on: Transition from pediatric to adult care*. Pediatric Transplantation, 2005. **9**(3): p. 364-372.
- 10. Freed, G.L. and E.J. Hudson, *Transitioning children with chronic diseases to adult care: Current knowledge, practices, and directions.* The Journal of pediatrics, 2006. **148**(6): p. 824-827.
- 11. Brown, M., Managing the acutely ill adult with sickle cell disease. British Journal of Nursing, 2012. 21(2): p. 90-96.
- 12. Rouse, C.M., *Informing choice or teaching submission to medical authority: a case study of adolescent transitioning for sickle cell patients*. Ethnicity & Health, 2011. **16**(4-5): p. 313-325.
- 13. Sickle Cell Disease Association of America. Available from: <u>http://www.sicklecelldisease.org/</u>.
- 14. Reiss, J.G., R.W. Gibson, and L.R. Walker, *Health Care Transition: Youth, Family, and Provider Perspectives*. Pediatrics, 2005. **115**(1): p. 112-120.

- 15. American Academy of Pediatrics and National Center for Medical Home Implementation. *Children & Youth With Special Health Care Needs (CYSHCN)*. [cited 2012 December 26]; Available from: http://www.medicalhomeinfo.org/how/care\_delivery/cyshcn.aspx.
- 16. American Academy of Pediatric Dentistry. *Definition of Special Health Care Needs*. 2012 [cited 2012 December 26]; Available from: <u>http://www.aapd.org/media/Policies\_Guidelines/D\_SHCN.pdf</u>.
- 17. Britto, M.T., et al., *Specialists Understanding of the Health Care Preferences of Chronically Ill Adolescents*. Journal of Adolescent Health, 2007. **40**(4): p. 334-341.
- 18. Sobota, A., et al., *Thirty-day readmission rates following hospitalization for pediatric sickle cell crisis at freestanding children's hospitals: Risk factors and hospital variation.* Pediatric Blood & Cancer, 2012. **58**(1): p. 61-65.
- 19. Child and Adolescent Health Measurement Initiative. National Survey of Children with Special Health Care Needs. Data Resource Center for Child and Adolescent Health., As cited in Children with Special Health Care Needs in California: A Profile of Key Issues, Lucile Packard Foundation for Children's Health (Jan. 2013).
- 20. Coleman, C., *Children's Health Coverage Under the ACA Part I: Inventory of Children's Health Programs*, Insured the Uninsured Project, Editor. 2014.
- 21. WISCH Transition Affinity Group Members, Working to Improve Sickle Cell HealthCare Recommended Curriculum for Transition from Pediatric to Adult Medical Care for Adolecents with Sickle Cell Disease: Suggested Topics, Methods, and Efficacy Measurements. 2013.
- 22. Tanabe, P., et al., *Emergency Department Sickle Cell Assessment of Needs and Strengths (ED-SCANS), a Focus Group and Decision Support Tool Development Project.* Academic Emergency Medicine, 2010. **17**(8): p. 848-858.
- 23. Burdo-Hartman, W.A. and D.R. Patel, *Medical Home and Transition Planning for Children and Youth with Special Health Care Needs*. Pediatric Clinics of North America, 2008. **55**(6): p. 1287-1297.
- 24. California Sickle Cell Resources. 2013 [cited 2014 March 1]; Available from: http://casicklecell.org/advocacy-corner.
- 25. Julia Evangelou Strait. *Into adulthood, sickle cell patients rely on ER*. 2012 [cited 2014 May 23]; Available from: http://news.wustl.edu/news/Pages/24677.aspx.
- 26. White, P.H., Access to Health Care: Health Insurance Considerations for Young Adults With Special Health Care Needs/Disabilities. Pediatrics, 2002. **110**(Supplement 3): p. 1328-1335.
- 27. Platt, O.S., et al., *Pain in Sickle Cell Disease*. New England Journal of Medicine, 1991. **325**(1): p. 11-16.
- 28. Wierenga, K.J.J., et al., *Survival estimates for patients with homozygous sickle-cell disease in Jamaica: a clinic-based population study.* The Lancet, 2001. **357**(9257): p. 680-683.
- 29. Quinn, C.T., Z.R. Rogers, and G.R. Buchanan, Survival of children with sickle cell disease. Vol. 103. 2004. 4023-4027.
- 30. Dampier, C., et al., *Health-related quality of life in adults with sickle cell disease (SCD): A report from the comprehensive sickle cell centers clinical trial consortium.* American Journal of Hematology, 2011. **86**(2): p. 203-205.

- 31. Kathleen B Bloomquist, *Health, Education, Work, and Independence of Young Adults With Disabilities.* Orthopaedic Nursing, 2006. **25**(3): p. 168-187.
- 32. Adams, S.H., et al., *Health Insurance Across Vulnerable Ages: Patterns and Disparities From Adolescence to the Early 30s.* Pediatrics, 2007. **119**(5): p. e1033-e1039.
- 33. Feinberg, E., et al., Family Income and the Impact of a Children's Health Insurance Program on Reported Need for Health Services and Unmet Health Need. Pediatrics, 2002. **109**(2): p. e29.
- 34. Gurvitz, M.Z., et al., *Changes in Hospitalization Patterns Among Patients With Congenital Heart Disease During the Transition From Adolescence to Adulthood.* Journal of the American College of Cardiology, 2007. **49**(8): p. 875-882.
- 35. Jan, S., et al., *Association of Hospital and Provider Types on Sickle Cell Disease Outcomes*. Pediatrics, 2013. **132**(5): p. 854-861.
- 36. Okumura M, et al., *Inpatient health care use among adult survivors of chronic childhood illnesses in the united states.* Archives of Pediatrics & Adolescent Medicine, 2006. **160**(10): p. 1054-1060.
- 37. Ronald M. Andersen, Thomas H. Rice, and Gerald F. Kominski, eds. *Changing the U.S. Health Care System: Key Issues in Health Services Policy and Management*. 3rd ed. 2011, John Wiley & Sons.
- 38. Adler, N.E. and K. Newman, *Socioeconomic Disparities In Health: Pathways And Policies*. Health Affairs, 2002. **21**(2): p. 60-76.
- 39. Haas, J.S., et al., Variation in Access to Health Care for Different Racial/Ethnic Groups by the Racial/Ethnic Composition of an Individual's County of Residence. Medical Care, 2004. **42**(7): p. 707-714.
- 40. Lotstein, D.S., et al., *The Transition to Adult Health Care for Youth With Special Health Care Needs: Do Racial and Ethnic Disparities Exist?* Pediatrics, 2010. **126**(Supplement 3): p. S129-S136.
- 41. Ameringer, S. and W.R. Smith, *Emerging Biobehavioral Factors of Fatigue in Sickle Cell Disease*. J Nurs Scholarship 2011. **43**(1): p. 22-29.
- 42. Laditka, J.N., S.B. Laditka, and M.P. Mastanduno, *Hospital utilization for ambulatory care sensitive conditions: health outcome disparities associated with race and ethnicity.* Social Science & amp; Medicine, 2003. **57**(8): p. 1429-1441.
- 43. Mehmet Rami Helvaci, Orhan Ayyildiz, and M. Gundogdu, *Gender differences in severity of sickle cell diseases in nonsmokers*. Pak J Med Sci, 2013. **29**(4): p. 1050-1054.
- 44. Elliot P Vichinsky. Pregnancy in women with sickle cell disease. Uptodate 2014 [cited 2014 March 3].
- 45. Oster, A. and A.B. Bindman, *Emergency Department Visits for Ambulatory Care Sensitive Conditions: Insights into Preventable Hospitalizations*. Medical Care, 2003. **41**(2): p. 198-207.
- 46. Berry JG, Hall D. E., and Kuo D. Z., *Hospital utilization and characteristics of patients experiencing recurrent readmissions* within children's hospitals. JAMA: The Journal of the American Medical Association, 2011. **305**(7): p. 682-690.

- 47. Wolfson, J.A., et al., *Sickle cell disease in California: Sociodemographic predictors of emergency department utilization*. Pediatric Blood & Cancer, 2012. **58**(1): p. 66-73.
- 48. Jervis, K.J., G.M. Goldberg, and A.C. Cutting, *Inner-City Hospital Closures: Financial Decision or Impediment to Access?* Journal of Health Care Finance, 2012. **38**(3): p. 22-39.
- 49. Want, H.-Y., et al., *The use of Charlson comorbidity index for patients revisiting the emergency department within 72 hours.* Chang Gung Med J, 2007. **30**(5): p. 437-44.
- 50. Kim, H., et al., *Scheduled and Unscheduled Hospital Readmissions among Diabetes Patients*. American Journal of Managed Care, 2010. **16**(10): p. 760-767.
- 51. Brousseau, D.C., et al., *Acute Care Utilization and Rehospitalizations for Sickle Cell Disease*. JAMA: The Journal of the American Medical Association, 2010. **303**(13): p. 1288-1294.
- 52. Halfon, P., et al., Validation of the Potentially Avoidable Hospital Readmission Rate as a Routine Indicator of the Quality of Hospital Care. Medical Care, 2006. **44**(11): p. 972-981.
- 53. Frei-Jones, M.J., J.J. Field, and M.R. DeBaun, *Risk factors for hospital readmission within 30 days: A new quality measure for children with sickle cell disease.* Pediatric Blood & Cancer, 2009. **52**(4): p. 481-485.
- 54. Thomas, J.W., *Does Risk-Adjusted Readmission Rate Provide Valid Information on Hospital Quality?* Inquiry, 1996. **33**(3): p. 258-270.
- 55. Liaw, W., et al., *The Impact of Insurance and a Usual Source of Care on Emergency Department Use in the United States.* International Journal of Family Medicine, 2014. **2014**: p. 5.
- 56. Bakshi, A., et al., *Validation of the care transition measure in multi-ethnic South-East Asia in Singapore*. BMC Health Services Research, 2012. **12**(1): p. 256.
- 57. Zlotnick, C. and L. Soman, *The impact of insurance lapse among low-income children*. Journal of Urban Health, 2004. **81**(4): p. 568-583.
- 58. Moore, C., T. McGinn, and E. Halm, *Tying up loose ends: Discharging patients with unresolved medical issues.* Archives of Internal Medicine, 2007. **167**(12): p. 1305-1311.
- 59. Sasha Shepperd, et al., *Discharge planning from hospital to home*. Cochrane Database Syst Rev., 2010. **20**(1).
- 60. Office of Statewide Health Planning & Development, Patient Discharge Data File Documentation Complete Files. 2006-2011.
- 61. Office of Statewide Health Planning & Development, *Emergency Department and Ambulatory Surgery Data File Documentation Complete Files*. 2006-2011.
- 62. Bindman, A.B., et al., *The Impact of Medicaid Managed Care on Hospitalizations for Ambulatory Care Sensitive Conditions*. Health Services Research, 2005. **40**(1): p. 19-38.
- 63. Hassell, K.L., *Population Estimates of Sickle Cell Disease in the U.S.* American Journal of Preventive Medicine. **38**(4): p. S512-S521.

- 64. Hin, L.-Y. and Y.-G. Wang, *Working-correlation-structure identification in generalized estimating equations*. Statistics in Medicine, 2009. **28**(4): p. 642-658.
- 65. Lisa Feuchtbaum, Susan Paulukonis, and N. Rosenthal. *RuSH: Sickle Cell Surveillance and Registry Program* Available from: http://www.aphl.org/conferences/proceedings/Documents/2013/2013-Newborn-Screening-Symposium/61Feuchtbaum.pdf.
- 66. Saul Weiner, "I Can't Afford That!" Dilemmas in the Care of the Uninsured. JGIM, 2001. 16.
- 67. Mainous, A.G., et al., *Impact of Insurance and Hospital Ownership on Hospital Length of Stay Among Patients With Ambulatory Care–Sensitive Conditions*. The Annals of Family Medicine, 2011. **9**(6): p. 489-495.
- 68. Joshua J Field, Elliott P Vichinsky, and Michael R DeBaun. *Overview of the management and prognosis of sickle cell disease*. UpToDate 2014; Available from: <u>www.uptodate.com</u>.
- 69. Susan Claster, et al., *Pitfalls of Using Administrative Data Sets to Describe Clinical Outcomes in Sickle Cell Disease*. Pediatric Blood & Cancer, 2013. **60**: p. 1936-1939.
- 70. Center for Disease Control and Prevention. *Sickle Cell Disease (SCD): Complications and Treatments*. January 17, 2014; Available from: <u>http://www.cdc.gov/ncbddd/sicklecell/treatments.html</u>.
- 71. Wang, C.J., et al., Quality-of-Care Indicators for Children With Sickle Cell Disease. Pediatrics, 2011. 128(3): p. 484-493.
- 72. Woods, K.F., et al., *Sickle cell disease telemedicine network for rural outreach*. Journal of Telemedicine and Telecare, 2000. **6**(5): p. 285-290.
- 73. Patik, M., et al., *Structured telephone-based outreach using nonmedical personnel can improve adherence to comprehensive care in families of children with sickle cell disease*. American Journal of Hematology, 2006. **81**(6): p. 462-464.
- 74. de Montalembert, M., et al., *ENERCA clinical recommendations for disease management and prevention of complications of sickle cell disease in children*. American Journal of Hematology, 2011. **86**(1): p. 72-75.
- 75. Sharon Silow-Carroll, Jennifer n. edwardS, and Aimee laShBrook. *Reducing Hospital Readmissions: Lessons from Top-Performing Hospitals Synthesis Report* • *April 2011*. 2011; Available from: <u>http://www.commonwealthfund.org/~/media/Files/Publications/Case%20Study/2011/Apr/1473\_SilowCarroll\_readmissions\_sy</u> <u>nthesis\_web\_version.pdf</u>.