HEALTH COSTS OF SICKLE CELL DISEASE PATIENTS

FROM THE MEDICAL EXPENDITURES PANEL

SURVEY, 1996-1997, 2002-2003, 2007-2008

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VICTORIA NKEM OJO

B.S., University of Missouri-Kansas City, 2009

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HEALTH COSTS OF SICKLE CELL DISEASE PATIENTS FROM THE MEDICAL EXPENDITURES PANEL SURVEY,

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Victoria Nkem Ojo, Candidate for the Master of Science Degree

University of Missouri-Kansas City, 2012

ABSTRACT

Chronic conditions affect a person physically, mentally, emotion, socially, and financially. With the increase in technology and advancements in medicine, those with chronic conditions are living longer and spending more money to do so. Using Medical Expenditure Panel Survey (MEPS) data, sickle cell disease (SCD), a chronic, inherited anemia, was described showing the cost to society and the personal cost to the patients. Regression analysis was used to compare SCD to both cystic fibrosis (CF), a chronic, inherited disease of the mucus glands and, a healthy population. This study will describe the difference in direct and indirect health costs of two comparable chronic diseases receiving differing research money. Results indicate that SCD patients and CF patients are not significantly different regarding health status or indirect health costs, however, SCD patients have less prescriptions and prescription costs than CF patients, which were expected due to the probability of the SCD population containing sickle cell trait patients.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of School of Medicine, have examined a thesis titled "Health Costs of Sickle Cell Disease Patients from the Medical Expenditure Panel Survey, 1996-1997, 2002-2003, 2007-2008," presented by Victoria Nkem Ojo, candidate for the Master of Science Bioinformatics degree, and certify that in their opinion it is worthy of acceptance.

Supervisory Committee

Mary M. Gerkovich, Ph.D., Committee Chair
Department of Biomedical and Health Informatics

William E. Lafferty, MD
Department of Biomedical and Health Informatics

Tim Hickman, M.D., M.Ed., MPH
Department of Biomedical and Health Informatics

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To my mother, Betty Nwabuonwu.

CHAPTER 1

INTRODUCTION

Costs associated with chronic conditions make up a disproportionate share of the health care expenditures in the United States.[1] By definition, a condition is deemed chronic when it has a long duration and, typically, a slow progression while limiting a person's daily activities and/or requiring ongoing medical care. Early on in modern health care, the focus was on treatment and prevention of infectious diseases like influenza and pneumonia. These diseases had high mortality and spread widely due to malnutrition, poor sanitation, and inadequate medical care. After an overhaul of the health system, introduction of vaccinations, and increased focus on public health conditions, there has been a clear decrease in mortality and morbidity of infectious diseases. However, the public health needs have shifted from acute infectious diseases to chronic conditions.

An estimated 133 million Americans, roughly 50%, had at least one chronic condition in 2005 and that number has only grown. It is projected that by 2020, 50% of the US population (about 164 million people) will have at least one chronic condition and 24% (about 81 million people) will have two or more.[2] Due to health care advancements in technology and research, people are living longer with multiple chronic conditions.[3] With more conditions comes higher financial burden. For a person with one or more chronic conditions, the average health care cost is five times greater than that of someone without any chronic condition. Along with financial burdens and physical limitations, there are also personal costs for those with chronic conditions. Poor health and complications often leave those with chronic conditions unable to attend school or work, contributing to poor performance and lower income potential. In addition, according to the Centers for Disease

Control and Prevention (CDC), Americans with chronic conditions account for 7 out of 10 deaths each year. Chronic conditions are a public health issue needing more research money and more attention if we are going to be able to make significant advances on the public health consequences of chronic diseases.

The National Institutes of Health (NIH) spends over $30.9 billion tax dollars on medical research. According to their website, there are 233 categories of research requested by Congress and other Federal agencies that are funded. With the focus shifting towards chronic conditions, one would hope that the research dollars would equally shift as well. However, due to politics and lack of public interest/knowledge, certain chronic conditions affecting many people are overshadowed and overlooked by chronic conditions affecting fewer people.

In order to better understand the cost to society and the personal costs to a patient with a chronic condition, sickle cell disease, a chronic, inherited form of anemia was chosen for analysis. This patient population was compared to patients with cystic fibrosis, a chronic, inherited disease of the mucus glands. In addition, the sickle cell disease patient sample was compared to a sample of people without any medical conditions to further show the high burden of chronic conditions. Furthermore, given the significant difference in research funding between the two chronic conditions, this project helps to shine a light on disparities in research funding in the context of the relative financial and personal cost of the two disease conditions.

CHAPTER 2

REVIEW OF LITERATURE

Over 90,000 Americans have been diagnosed with sickle cell anemia disease (SCD) and the numbers are increasing. According to the Centers for Disease Control and Prevention (CDC), one out of every 500 African-American births has SCD and one out of every 36,000 Hispanic-American births has SCD. Sickle cell anemia disease is not what some call a 'black disease', only affecting African-Americans. This painful chronic disease can be seen in those with a Caribbean, South American, Mediterranean, Arabian, East Indian and Central American background. SCD is a common, yet debilitating, disease affecting more Americans than other common genetic diseases like cystic fibrosis and hemophilia.[4] With no cure and more money being given to diseases that are less prevalent, ongoing research on sickle cell anemia disease is important.

Definition of Sickle Cell Disease

Sickle cell anemia disease (SCD) is a chronic, inherited form of anemia caused by a mutation of the beta-globin gene called sickle hemoglobin (HbS).[5,6] Due to the autosomal recessive nature of the allele, disease expression happens with two Hb S or one Hb S and hemoglobin with a mutation of the beta-globin gene (ex. Hb C and beta thalassemia).[7] Instead of round, soft red blood cells, SCD patients produce sickle-shaped red blood cells. These sickled cells last only 10-20 days, not allowing the bone marrow enough time to adequately replace the sickled cells by creating more cells.[8,9] Due to this sickled shape, many varying complications arise including crisis pain episodes (sickle cells block the blood flow), clogged spleen, and higher propensity for infection, etc.[10,11]

Although there is no proven method of preventing crises and other serious complications for SCD patients, there are suggested ways to reduce the amount and severity of complications. It is suggested that patients have regular physical exams and full blood work every 3-6 months as well as keep all regular medical appointments.[9] Patients are encouraged to stay away from extreme heat or cold as this will increase the risk of dehydration and oxygen loss which can lead to an increased production of sickled cells. Excessive exercising is discouraged due to the increased demand for oxygen and high possibility of dehydration.[10] Vaccinations are recommended for all sickle cell patients due to their compromised immune systems. All child SCD patients should have their childhood vaccinations and even some prophylactic antibiotics to increase protection from serious infections.[9,11] It is now common practice to give babies with SCD daily penicillin from age 2 months to 5 years.[12]

Although there is no cure for SCD, researchers and doctors have found ways to improve the quality of life of patients. A typical measure of the quality of life of sickle cell patients are their number and severity of pain episodes. In about 90% of SCD patients, treatment of these pain episodes is the main reason for hospital admission.[13] Hospital admissions are not the only indicator of health status among patients for various reasons. Patients often avoid hospitalization because they do not like or trust doctors, they do not see a need for hospital visits, or they cannot afford as many hospital visits as they would actually need.[14,15,16] While there is no cure for the 90,000+ Americans with SCD, research is estimated to be 75 million dollars for the fiscal year of 2012, is ongoing and needed to improve treatment options as well as to identify a potential cure.[20]

Definition of Cystic Fibrosis

Cystic Fibrosis (CF) is a chronic, inherited disease of the mucus glands caused by a mutation of the cystic fibrosis transport regulator gene.[17] Due to the autosomal recessive nature of this disease, it is necessary for patients to have mutations of both copies of the gene. Instead of thin, free-flowing mucus, CF patients' cells that line the lungs, digestive tract, and other organs produce unusually thick, sticky mucus.[18] This mucus can clog certain vital pathways causing lung infections and digestive problems. This painful chronic disease is the most common within the Caucasian community in the United States, affecting those with a Northern or Central European background.[19] Although there is not cure for the 30,000+ Americans with CF, patients are expected to live well into their 40s and beyond, and an estimated 88 million dollars in research funding is budgeted for the fiscal year of 2012.[16]

Cystic fibrosis is a comparable disease to SCD because they are both chronic, autosomal recessive diseases that complicate the lives of patients. Both conditions require patients to frequent the doctor's office as well as the hospital for treatment. Without a cure, both sets of patients are advised on different tactics to reduce the instances and severity of an episode; crisis pain for SCD and severe lung infections for CF. Daily medicine intake and monitoring food and water intake are a part of the lives of SCD and CF patients, and have a significant impact on their quality of life. While both diseases have high mortality rates, life expectancy is dependent upon the severity of the condition and the time of diagnosis.[20]

Cost of Sickness and Research Funding

With many patients not being able to afford out-of-pocket payment or health insurance, some patients choose to not seek necessary medical care and/or skip daily medicine. The cost of sickness is high when you factor in wages lost due to doctor visits and

sick days, time taken off to take care of a family member with a chronic condition, the reduction in quality of life, and eventual premature death. Even though mortality and morbidity has decreased, SCD patients need medical care at a high rate.[21,22] A 2009 study showed that the annual cost of medical care in the US for SCD patients is more than $1.1 billion, about $16,000 in medical expenses a year for each patient.[23] With most of the cost being paid through government funded programs, it would be beneficial in terms of decreased cost to society in the long run if more resources were focused on identifying methods to prevent, cure, or treat the disease in a manner that would avoid rising hospital utilization.

Given that SCD affects approximately three times the number of people who are affected by CF, the disparity in government research funding through NIH is clearly seen through the estimated funding figures for the 2012 fiscal year (SCD: $65 million vs CF: $79 million). The gap in funding has ranged from $10 to $38 million from 2004 to 2012, with the projected 2013 funding continuing an estimated $14 million gap.[16] To get a clearer image of the disparity, NIH spends nearly 4 times the amount of money for each CF patient compared to that spent on each SCD patient. Although NIH is not the only source of research funding for medical conditions, it is a major source so that any disparity in NIH funding is felt on a large scale by any underfunded disease.

The disparity is much greater in terms of private funding. In 2010, the Cystic Fibrosis Foundation reported annual revenue of $313,308,873 compared to $1,528,350, in annual revenue for the same year for the Sickle Cell Disease Association of America, Inc.[24,25] When both government and private funding is considered together, there is a $325 million difference in available funds for 2010. Not only does funding go to research purposes but

with more money, charities are able to mobilize to help families of disease-suffers as well as educate the general public.

History of MEPS

The Medical Expenditure Panel Survey (MEPS) is a dataset of nationwide surveys conducted by the Agency for Healthcare Research and Quality (AHRQ), the U.S. Department of Health and Human Services (DHHS), and the National Center for Health Statistics (NCHS). Medical expenditure data collection using surveys began in the 1970s when changes were taking place regarding the structure of health care services, private insurance, government-sponsored health care programs and the U.S. population. The survey sample design includes multistage sample selection, clustering, and stratification in order for the sample to provide representative national estimates. In 1977, the National Medical Care Expenditure Survey (NMCES) was conducted. This survey included a household survey, a survey of physicians utilized by the household members, and a survey about employer health insurance. Over a 14-month period, 14,000 households participated in six rounds of interviews. Ten years later, in 1987, the National Medical Expenditure Survey (NMES) was conducted. This time, 16,000 households participated, answering surveys regarding their household, medical providers, and health insurance used by participants. In 1996, the current MEPS survey was designed, surveying households every year instead of every ten years.

The MEPS survey is composed of two main components: the Household Component and the Insurance Component. The Household Component (HC) contains information on each individual in the sample household including demographics, health conditions, health status, use of medical services, charges and source of payments, access to care, satisfaction with care, health insurance coverage, income, and employment. Each household is surveyed

and interviewed during several rounds covering a 24-month period. The Insurance Component (IC), also known as the Health Insurance Cost Study, contains data on private and public sector employer health insurance plans offered to their respective employees. The information on the health insurance plans includes premiums, types of plan(s), amount contributed by employee/employer, eligibility requirements, benefits attached to the plan, and employer characteristics.[26]

Uses of MEPS

With all the data available in a MEPS dataset, there are multiple possible uses. Researchers can ask questions about use of, access to and expenditures for health care; it is even possible to ask the source of payment.[26] These questions may be of interest to researcher if they are looking at the changes over time regarding a certain health status and/or health condition. Policy makers would be able to use MEPS to see the impact on coverage and financing as well, as whom it affects if a certain policy were modified. With the special breakdown of certain populations, researchers can focus in on the elderly, ethnic groups, veterans, the uninsured, and those below the poverty line.[25]

Summary

Sickle cell anemia disease is a disease that affects tens of thousands of individuals in America. Without a cure, like cystic fibrosis patients, sickle cell patients are left to take medicines and follow regimens in order to stay out of the emergency room and hospital. This project describes the cost to society and the personal cost to sickle cell patients. As a comparison, the medical expenditures for another patient population, those with CF, were also examined. The purpose of this thesis is to define the SCD patient population using MEPS data and compare the SCD population with another disease population of similar

morbidity and costs. The comparison of the SCD population with those without any medical condition serve as a method of validating the measures used to compare the two patient samples by verifying that the cost and utilization measures for SCD patients are significantly more than those for patients with no diagnosed conditions. Given the relative size of the SCD and CF patient populations (90,000+ vs. 30,000+, respectively), and the relative size of research funding anticipated for 2012 ($65 million vs. $79 million, respectively), the comparison might provide evidence of the need for further research support for the SCD patient population.

CHAPTER 3

METHODOLOGY

Study Samples

For this study, data on SCD, CF, and healthy patients for two-year time blocks were used. These years were pooled to generate a larger sample size. Data from these years are expected to serve as valid representation of information across the entire time range of MEPS survey collection. The study was approved as exempt by the University of Missouri – Kansas City Adult Health Sciences Institutional Review Board (Protocol #12-05).

Inclusion and Exclusion Criteria

All data were drawn from MEPS data files and represented U.S. non-institutionalized civilians with positive person-level weights. A respondent would receive a non-positive person-level weight if they were either not part of the target population (i.e., U.S. non-institutionalized civilians) or were not "inscope" (i.e., not available for data collection) during any part of the survey year. The target diagnosis population for this study was sickle cell patients in the United States. Sickle cell anemia disease patients were limited to respondents who indicated a medical condition diagnosis that falls within the sickle cell anemia disease clinical classification code.

Comparison Populations

CF patients were limited to respondents who indicated a medical condition diagnosis that falls within the cystic fibrosis clinical classification code. Healthy patients were those with no medical condition indicated.

Procedure

Participants were selected using MEPS data. Eligible individuals who fell within the target or comparison population categories, SCD, CF, or health were identified from each of the following years: 1996, 1997, 2002, 2003, 2007, or 2008.

Dependent Variables

As part of this study, two groups of expenditures were used, Direct Costs and Indirect Costs.

Direct Costs. Direct costs take into account the medical expenditures by the patient population. Direct cost was defined using the total health service expenditures variable (TOTEXP). MEPS constructs this variable using expenditures for office based care, hospital based care, home health care, dental services, vision aids, and prescription medicines.

Indirect Costs. Indirect costs take into account disability days. Indirect cost was defined as days of worked missed and days of school missed. MEPS constructs this using the number of work days missed where respondent spent at least half-day in bed (WKINBD) for participants 16 or over; the number of school days missed where respondent spent at least half-day in bed (SCLNBD); and for those who did not work or go to school, there was a variable (DDBDYS) that represented days in which the participant spent at least half a day in bed due to illness, injury, or mental/emotional problems.

As a secondary comparison, health status is compared between SCD patients and CF patients.

Health Status. Health status took into account medical care and hospital utilization. Health status was defined as follows:

- ERTOT - the number of emergency room visits.
- RXTOT - number of prescription medicines used including refills.
- OPDRV - number of outpatient department visits where a physician was not seen.
- OPOTHV - number of outpatient department visits where a non-physician was seen.
- OBTOTV - number of office-based provider visits.
- OBTHER - number of office-based physical/occupational therapist visits.
- OBOPTO - number of office-based optometrist visits.
- OBNURS - number of office-based nurse and/or nurse practitioner visits.
- OBDRV - number of office-based physician visits.
- OBCHIR - number of office-based chiropractor visits.
- IPZERO - number of zero-night hospital stays.
- IPNGTD - number of nights in hospital for discharges.
- IPDIS - number of hospital discharges.
- HHAGD - number of agency home health provider days.
- DVTOT - number of dental care visits.
- DVGEN - number of general dentist visits.
- AMNURS - number of ambulatory nurse/nurse practitioner visits (outpatient and office based).
- AMTHER - number of ambulatory physical/occupational therapist visits (outpatient and office based).
- AMOPTO - number of ambulatory optometrist visits (outpatient and office based).
- AMCHIR - number of ambulatory chiropractor visits (outpatient and office based).

Covariates

Healthcare disparities among ethnic minorities are often due to ethnic minorities being disproportionately more likely to be of a lower socioeconomic status. To control for these confounding effects, the covariates included age, gender, ethnicity, and source of healthcare coverage. The coding values of each variable are as follows:

- Age – Age was used as a continuous variable ranging from 0 to 85 (ages over 85 years are coded as 85 in MEPS for confidentiality).
- Gender – Female or male.
- Ethnicity – Hispanic, Black (Not Hispanic), Asian (Not Hispanic), or Other Race (Not Hispanic). Note that the "Other Race" category includes the Caucasians/White population.
- Health insurance coverage – Uninsured all year or having health insurance.
- Education – Education was used as a continuous variable reflecting number of years of education, and ranged from 0 to 17.

Independent Variable

The independent variable was a grouping variable that represented the diagnosis categorization as follows:

Sickle Cell Patients – indicated sickle cell disease as medical condition (SCD patients)

Cystic Fibrosis Patients– indicated cystic fibrosis as medical condition (CF patients)

Healthy Patients – did not have any medical condition (Healthy patient)

Statistical Analysis

All statistical analyses were completed using SPSS and SAS. The SAS procedures SURVEYFREQ and SURVEYMEANS were used for the descriptive statistics while SURVEYREG was used to determine whether there were significant differences between the SCD group and either of the two comparison groups after controlling for covariates. Regression was chosen to address the following questions: a) whether the SCD and CF patient populations are comparable in terms of health status and costs; and b) whether SCD patients have significantly higher healthcare costs and significantly poorer health status compared to the healthy population. A grouping variable served as the predictor variable in the regression analyses, allowing the CF patients and the healthy population to each be compared to the SCD patients. Due to the nature of MEPS survey design, three weighting variables (person level, cluster, and sampling strata) were used in order to properly analyze the data and allow national estimates to be computed. In order to create the proper population estimates over the multiple years, the person-level weight variable was divided by six, the number of years in the data set. The purpose of this was to adjust the weighting factor so that it took into account the multiple years of data in order to provide accurate population estimates. Statistical significance was set at alpha = .05 level.

CHAPTER 4

RESULTS

Sample Characteristics

Sickle Cell Disease Population. Medical condition data indicated 85 participants reported SCD as a medical condition over the six years that were examined. A total of 79 people had positive person-weight values and were included in the analysis. These 79 people represented 102,469 sickle cell patients. Demographic characteristics of this patient population are shown in Table 1. Ages ranged from 0 to77, with an average age of 21.8. The sample was predominately female (58%). The predominate ethnicity of SCD participants was Black (94%), in line with the demographic most effected by the disease. Others identified themselves as Hispanic (5%) and Asian (1%). Forty percent of the population were under 16 and were not asked about marital status; 29,553 participants were married (29%) and 21% were never married. A majority of the SCD population lived in the Southern region of the United States which is probably simply a reflection of the ethnicity distribution. The majority of SCD patients who were at least school age had at least a high school education. The majority of SCD patients (93%) were insured.

TABLE 1

DEMOGRAPHIC CHARACTERISTICS FOR SICKLE CELL DISEASE POPULATION

(WEIGHTED N = 102,469)

Variable	Mean	Std Error of Mean	95% CL for Mean
Age (mean):	21.8	1.87	18.09-25.43

Variable	Weighted	Percent
Gender:		
Male	43,207	42%
Female	59,261	58%
Ethnicity:		
Hispanic	4,935	5%
Black (Not Hispanic)	95,957	94%
Asian (Not Hispanic)	15,77	2%
White/Other Race (Not Hispanic)	0	0%
Marital Status:		
Married	29,553	29%
Widowed	0	0%
Divorced	4,197	4%
Separated	5,697	6%
Never Married	21,639	21%
Under 16-Inapplicable	41,382	40%
Region:		
Northeast	22,512	22%
Midwest	16,820	16%
South	56,651	55%
West	5,330	5%
Missing	1,155	1%

Variable	Weighted	Percent
Education:		
No School/Kindergarten Only	39,221	38%
Grades 1-8	11,222	11%
Grades 9-11	12,921	13%
Grade 12	28,090	27%
1 Year College	0	0%
2 Years College	9,334	9%
3 Years College	0	0%
4 Years College	1,682	2%
5+ Years College	0	0%
Insured:		
No	6,787	7%
Yes	95,682	93%

Cystic Fibrosis Population. Medical condition data indicated 43 participants reported CF as a medical condition over the six years that were examined. All 43 people had positive person-weight values and were included in the analysis, representing 88,428 cystic fibrosis patients. Demographic characteristics of this patient population are shown in Table 2. Ages ranged from 0 to 80, with an average age of 35. The sample was predominately female (81%). The predominant ethnicities of CF participants were Asian (48%) and White/Other Race (48%). Thirty-two percent of the population were under 16 and were not asked about marital status; 46,941 participants were married (53%). Although the majority of the CF population was from the Southern region of the United States, the rest of the CF population was evenly spread between the Midwest, West, and Northeast. The majority of CF patients who were at least school age had at least high school education. All CF patients were insured at some point during the survey year.

TABLE 2

DEMOGRAPHIC CHARACTERISTICS

FOR CYSTIC FIBROSIS POPULATION (WEIGHTED N = 88,428)

Variable	Mean	Std Error of Mean	95% CL for Mean
Age (mean):	35.0	5.13	24.98-45.103

Variable	Weighted N	Percent
Gender:		
Male	16,892	19%
Female	71,536	81%
Ethnicity:		
Hispanic	2,581	3%
Black (Not Hispanic)	1,305	1%
Asian (Not Hispanic)	42,418	48%
White/Other Race (Not Hispanic)	42,123	48%
Marital Status:		
Married	46,941	53%
Widowed	7,441	8%
Divorced	2,132	2%
Separated	1,653	2%
Never Married	2,258	3%
Under 16-Inapplicable	28,004	32%
Region:		
Northeast	13,019	15%
Midwest	19,301	22%
South	36,366	41%
West	19,742	22%

Variable	Weighted N	Percent
Education:		
No School/Kindergarten Only	45,244	51%
Grades 1-8	0	0%
Grades 9-11	2,460	3%
Grade 12	20,331	23%
1 Year College	2,195	2%
2 Years College	4,007	5%
3 Years College	0	0%
4 Years College	5,584	6%
5+ Years College	8,607	10%
Insured:		
No	0	0%
Yes	88,428	100%

Healthy Population. Medical condition data indicated 37,575 participants reported having no medical condition over the six years that were examined. A total of 33,990 people had positive person-weight values and were included in the analysis. These 33,990 people represented 45,272,438 healthy patients. Demographic characteristics of this patient population are shown in Table 3. Ages ranged from 0 to 85 years, with an average age of 28.3. The sample was predominately male (60%). The predominant ethnicity of healthy participants was White/Other Race (37%), others identified themselves as Hispanic (23%), Asian (21%), and Black (18%). Most of the participants were either married (35%) or never married (29%); 27% were under 16 and were not asked about marital status. Healthy participants were predominantly from the South and the West regions. The majority of healthy patients who were at least school age had at least high school education. Twenty-five percent of subjects were uninsured during the entire survey year leaving 75% who had some sort of health insurance at some point during the survey year.

Comparison of Samples. The CF patient population was older than the SCD population (35 years vs 22 years). The CF population had a much higher proportion of females (81%) compared to the SCD and healthy populations (58% and 40%, respectively). The ethnic breakdowns of the SCD and Healthy populations were as expected; the ethnic breakdown of the CF population, however, indicated a higher proportion of Asians than would be expected from the general population.

TABLE 3

DEMOGRAPHIC CHARACTERISTICS

FOR HEALTHY POPULATION (WEIGHTED N = 45,272,438)

Variable	Mean	Std Error of Mean	95% CL for Mean
Age (mean):	28.3	0.15	27.97-28.56

Variable	Weighted N	Percent
Gender:		
Male	26,953,538	60%
Female	18,318,900	40%
Ethnicity:		
Hispanic	10,595,868	23%
Black (Not Hispanic)	8,374,543	18%
Asian (Not Hispanic)	9,526,024	21%
White/Other Race (Not Hispanic)	16,776,003	37%
Marital Status:		
Married	15,690,729	35%
Widowed	721,635	2%
Divorced	2,605,299	6%
Separated	634,533	1%
Never Married	13,345,225	29%
Under 16-Inapplicable	12,209,061	27%
Missing	65,956	1%
Region:		
Northeast	8,607,929	19%
Midwest	8,229,929	18%
South	16,848,144	37%
West	11,106,806	25%
Missing	479,630	1%

Variable	Weighted N	Percent
Education:		
No School/Kindergarten Only	12,357,329	27%
Grades 1-8	7,814,736	17%
Grades 9-11	5,229,422	12%
Grade 12	9,102,584	20%
1 Year College	1,686,081	4%
2 Years College	2,857,409	6%
3 Years College	990,304	2%
4 Years College	3,397,497	8%
5+ Years College	1,837,077	4%
Insured:		
No	11,144,044	25%
Yes	34,128,394	75%

Cost and Health Status Outcomes

Summary statistics for each of the cost outcomes variables are shown for the SCD population (Table 4), CF population (Table 5) and healthy population (Table 6). Results of the regression analyses for each of these outcome variables, in which the SCD patient population was compared to the CF and health populations, are reported below.

TABLE 4

MEANS AND OUTCOMES FOR SICKLE CELL DISEASE POPULATION

Variable	Mean	Std Error of Mean	95% CL for Mean	
Direct Cost:				
Total Medical Expenditure	$5,825.25	2,094.14	1,716.77	9,933.72
Total Prescription Expenditure	$611.57	146.36	324.43	898.71
Indirect Cost:				
Total Disability Days	5.69	1.60	2.56	8.83
Health Status:				
# ER Visits	0.83	0.20	0.44	1.23
# Prescribed Meds	15.58	3.30	9.11	22.05
# Outpatient Department Non-Physician Visits	0.58	0.23	0.14	1.03
# Outpatient Department Physician Visits	0.52	0.15	0.22	0.81
# Office-based Provider Visits	9.99	4.25	1.65	18.33
# Office-based Physical/Occupational Therapy Visits	0.26	0.23	-0.20	0.72
# Office-based Non-Physician Visits	4.22	3.31	-2.28	10.72
# Office-based Optometrist Visits	0.02	0.01	-0.005	0.05
# Office-based Nurse/Nurse Practitioner Visits	0.06	0.03	0	0.11
# Office-based Physician Visits	5.77	1.25	3.31	8.22
# Office-based Chiropractor Visits	0.07	0.07	-0.07	0.22

Variable	Mean	Std Error of Mean	95% CL for Mean	
# Zero-night Hospital Stays	0.03	0.02	-0.01	0.06
# Nights in Hospital for Discharges	1.68	0.49	0.71	2.65
# Hospital Discharges	0.36	0.10	0.17	0.56
# Agency Home Health Provider Days	1.56	1.14	-0.68	3.80
# Dental Care Visits	0.37	0.11	0.16	0.58
# General Dentist Visits	0.29	0.09	0.13	0.46
# Ambulatory Physical/Occupational Therapist Visits (outpatient and office based)	0.43	0.29	-0.15	1.01
# Ambulatory Nurse/Nurse Practitioner Visits (outpatient and office based),	0.03	0.02	-0.01	0.06
# Ambulatory Optometrist Visits (outpatient and office based)	0.05	0.03	-0.01	0.10
# Ambulatory Chiropractor visits (outpatient and office-based)	0.03	0.02	-0.01	0.06

TABLE 5

MEANS AND OUTCOMES FOR CYSTIC FIBROSIS POPULATION

Variable	Mean	Std Error of Mean	95% CL for Mean	
Direct Cost:				
Total Medical Expenditure	$10,520.00	2,997.97	4,637.95	16,401.34
Total Prescription Expenditure	$4,914.08	1,857.12	1,270.62	8,557.54
Indirect Cost:				
Total Disability Days	7.81	4.42	-0.87	16.48
Health Status:				
# ER Visits	0.51	0.17	0.18	0.85
# Prescribed Meds	33.72	7.34	19.33	48.12
# Outpatient Department Non-Physician Visits	0.41	0.11	0.20	0.62
# Outpatient Department Physician Visits	0.61	0.25	0.11	1.11
# Office-based Provider Visits	7.80	1.20	5.44	10.15
# Office-based Physical/Occupational Therapy Visits	0.16	0.11	-0.06	0.39
# Office-based Non-Physician Visits	1.60	0.40	0.83	2.38
# Office-based Optometrist Visits	0.08	0.04	-0.01	0.16
# Office-based Nurse/Nurse Practitioner Visits	0.09	0.06	-0.02	0.21

Variable	Mean	Std Error of Mean	95% CL for Mean	
# Office-based Physician Visits	6.19	1.00	4.23	8.16
# Office-based Chiropractor Visits	0.03	0.03	-0.02	0.09
# Zero-night Hospital Stays	0.01	0.01	-0.01	0.04
# Nights in Hospital for Discharges	2.88	2.43	-1.89	7.66
# Hospital Discharges	0.58	0.39	-0.17	1.34
# Agency Home Health Provider Days	4.91	2.71	-0.41	10.22
# Dental Care Visits	1.07	0.27	0.54	1.59
# General Dentist Visits	0.86	0.20	0.46	1.26
# Ambulatory Physical/Occupational Therapist Visits (outpatient and office based)	0.08	0.08	-0.07	0.23
# Ambulatory Nurse/Nurse Practitioner Visits (outpatient and office based),	0.07	0.06	-0.03	0.18
# Ambulatory Optometrist Visits (outpatient and office based)	0.06	0.04	-0.02	0.13
# Ambulatory Chiropractor visits (outpatient and office-based)	0.01	0.01	-0.01	0.02

TABLE 6

MEANS AND OUTCOMES FOR HEALTHY PATIENT POPULATION

Variable	Mean	Std Error of Mean	95% CL for Mean	
Direct Cost:				
Total Medical Expenditure	$203.07	12.84	177.87	228.26
Total Prescription Expenditure	$4.00	0.48	3.05	4.94
Indirect Cost:				
Total Disability Days	0.12	0.04	0.05	0.19
Health Status:				
# ER Visits	0.0023	0.0003	0.002	0.003
# Prescribed Meds	0.09	0.01	0.07	0.10
# Outpatient Department Non-Physician Visits	0.01	0.001	0.01	0.01
# Outpatient Department Physician Visits	0.01	0.001	0.005	0.01
# Office-based Provider Visits	0.38	0.01	0.37	0.40
# Office-based Physical/Occupational Therapy Visits	0.10	0.01	0.09	0.11
# Office-based Non-Physician Visits	0.03	0.002	0.02	0.03
# Office-based Optometrist Visits	0.03	0.002	0.02	0.03
# Office-based Nurse/Nurse Practitioner Visits	0.28	0.01	0.27	0.29
# Office-based Physician Visits	0.01	0.002	0.004	0.01
# Office-based Chiropractor Visits	0.002	0.0003	0.001	0.003

Variable	Mean	Std Error of Mean	95% CL for Mean	
# Zero-night Hospital Stays	0.01	0.003	0.005	0.015
# Nights in Hospital for Discharges	0.002	0.0003	0.001	0.002
# Hospital Discharges	0.004	0.002	-0.001	0.009
# Agency Home Health Provider Days	0.56	0.01	0.53	0.58
# Dental Care Visits	0.42	0.009	0.40	0.44
# General Dentist Visits	0.00002	0.00002	0	0.0001
# Ambulatory Physical/Occupational Therapist Visits (outpatient and office based)	0.027	0.002	0.024	0.031
# Ambulatory Nurse/Nurse Practitioner Visits (outpatient and office based),	0.02	0.002	0.021	0.027
# Ambulatory Optometrist Visits (outpatient and office based)	0.008	0.002	0.004	0.01
# Ambulatory Chiropractor visits (outpatient and office-based)	0.002	0.0003	0.001	0.002

Group Differences in Costs and Health Status Outcomes

Regression analyses were performed in order to identify whether either comparison population was significantly different from the sickle cell disease population in terms of each cost and health status outcome variables. For each of these analyses, the group predictor variable was tested after controlling for age, sex, race, number of years of education, and insurance status. The structure of the regression analysis allowed both the CF and healthy populations to be uniquely tested against the SCD population. It was expected that the SCD patient population would have higher cost values compared to the healthy population. Tables 7 through 17 show the results of the regression analyses for those cost and health status outcome variables in which there was a significant difference between the SCD population and either the CF or health population.

Total Prescription Expenditures. After adjusting for the control variables of ages, gender, ethnicity, education, and insurance status, the SCD patient population had significantly lower prescription expenditures than the CF population and significantly higher prescription expenditures than the healthy population (Table 7).

Number of Prescribed Medicines. These significant differences in prescription costs were also reflected in the significant difference in the total number of prescriptions each population reported taking (Table 8). SCD patients reported having an average of 16 prescriptions compared to 34 prescriptions reported by the CF population and less than 1 prescription on average reported by the healthy population.

TABLE 7

ESTIMATED REGRESSION COEFFICIENTS FOR TOTAL PRESCRIPTION EXPENDITURES

Variable	B	SEB	t	p≤ t
Groups:				
CF	4303.75	1857.871	2.32	0.0207
Healthy	-606.941	147.2074	-4.12	<.0001
SCD	ref			
Age	-0.33469	0.21766	-1.54	0.1244
Gender:				
Female	-7.10098	3.83121	-1.85	0.0641
Male	ref			
Ethnicity:				
Hispanic	-21.5409	8.88875	-2.42	0.0155
Black (Not Hispanic)	-18.9414	8.34655	-2.27	0.0234
Asian (Not Hispanic)	-35.1278	15.54575	-2.26	0.024
White/Other Race (Not Hispanic)	ref			
Education	-0.58585	0.67268	-0.87	0.384
Insured				
No	0.72361	1.71197	0.42	0.6726
Yes	ref			
Intercept	645.0656	148.6077	4.34	<.0001

TABLE 8

ESTIMATED REGRESSION COEFFICIENTS FOR TOTAL PRESCRIPTIONS

Variable	B	SEB	t	p≤ t
Groups:				
CF	18.03422	7.874195	2.29	0.0222
Healthy	-15.5147	3.301362	-4.7	<.0001
SCD	ref			
Age	0.00039	0.001097	0.36	0.7223
Gender:				
Female	-0.1666	0.025864	-6.44	<.0001
Male	ref			
Ethnicity:				
Hispanic	-0.12231	0.034043	-3.59	0.0003
Black (Not Hispanic)	-0.1278	0.039722	-3.22	0.0013
Asian (Not Hispanic)	-0.12086	0.062132	-1.95	0.052
White/Other Race (Not Hispanic)	ref			
Education	0.001515	0.003325	0.46	0.6488
Insured				
No	-0.02708	0.015177	-1.78	0.0747
Yes	ref			
Intercept	15.76043	3.302377	4.77	<.0001

For all other cost outcome variables, SCD and CF patient populations were not significantly different. The cost outcome variables in which the SCD and healthy populations were significantly different are presented below and shown in Tables 9 through 17.

As expected, the healthy population had significantly lower total medical expenditures compared to the SCD population ($203 versus $5825, respectively; Table 9). SCD patients had higher average disability days than did the healthy population (6 days versus <1 day, respectively; Table 10). The SCD population also had significantly higher utilization of the health care system than did the healthy population. While the SCD patient population averaged less than one emergency room visit during the year, their use was significantly higher than the healthy population (.8 versus <.01, respectively; Table 11). In terms of outpatient and office-based visits, the SCD patient population had more outpatient and office-based visits had more outpatient department non-physician visits (.6 versus <.01, respectively; Table 12), more outpatient physician visits (.5 versus <.01, respectively; Table 13), more office-based provider visits (10 versus .4, respectively; Table 14), and more office-based physician visits (6 versus <.01, respectively; Table 15). While the SCD patient population averaged less than one hospital discharge during the year, their use was significantly higher than the healthy populations (.4 versus <.01, respectively; Table 16) and they had more nights spent in a hospital than did the healthy population (2 versus <.01, respectively; Table 17).

TABLE 9

ESTIMATED REGRESSION COEFFICIENTS FOR TOTAL MEDICAL EXPENDITURES

Variable	B	SEB	t	p≤ t
Groups:				
CF	4605.297	3654.261	1.26	0.2078
Healthy	-5640.03	2095.052	-2.69	0.0072
SCD	ref			
Age	-0.7761	0.88657	-0.88	0.3816
Gender:				
Female	-53.676	27.20207	-1.97	0.0487
Male	ref			
Ethnicity:				
Hispanic	-165.639	44.22639	-3.75	0.0002
Black (Not Hispanic)	-168.455	45.52836	-3.7	0.0002
Asian (Not Hispanic)	-175.982	47.90849	-3.67	0.0002
White/Other Race (Not Hispanic)	ref			
Education	-1.2201	3.01221	-0.41	0.6855
Insured				
No	-154.156	12.40324	-12.43	<.0001
Yes	ref			
Intercept	6051.643	2088.727	2.9	0.0038

TABLE 10

ESTIMATED REGRESSION COEFFICIENTS FOR TOTAL DISABILITY DAYS

Variable	B	SEB	t	p≤ t
Groups:				
CF	2.0741	4.713071	0.44	0.66
Healthy	-5.66062	1.595929	-3.55	0.0004
SCD	ref			
Age	-0.00206	0.001457	-1.41	0.1586
Gender:				
Female	0.035548	0.053918	0.66	0.5098
Male	ref			
Ethnicity:				
Hispanic	-0.22368	0.149269	-1.5	0.1343
Black (Not Hispanic)	-0.19653	0.111967	-1.76	0.0795
Asian (Not Hispanic)	-0.21754	0.113185	-1.92	0.0548
White/Other Race (Not Hispanic)	ref			
Education	0.003225	0.005108	0.63	0.5278
Insured				
No	0.140305	0.16359	0.86	0.3912
Yes	ref			
Intercept	5.890388	1.596235	3.69	0.0002

TABLE 11

ESTIMATED REGRESSION COEFFICIENTS FOR NUMBER OF EMERGENCY ROOM VISITS

Variable	B	SEB	t	p≤ t
Groups:				
CF	-0.31673	0.262591	-1.21	0.228
Healthy	-0.82814	0.200869	-4.12	<.0001
SCD	ref			
Age	-1.7E-05	3.2E-05	-0.52	0.6066
Gender:				
Female	-0.00043	0.000961	-0.45	0.6558
Male	ref			
Ethnicity:				
Hispanic	-0.00085	0.001021	-0.83	0.4078
Black (Not Hispanic)	0.000697	0.001187	0.59	0.5572
Asian (Not Hispanic)	-0.00341	0.001465	-2.33	0.0201
White/Other Race (Not Hispanic)	ref			
Education	-0.00011	0.000101	-1.11	0.269
Insured				
No	-0.00042	0.000959	-0.43	0.664
Yes	ref			
Intercept	0.832953	0.200439	4.16	<.0001

TABLE 12

ESTIMATED REGRESSION COEFFICIENTS FOR TOTAL OUTPATIENT DEPARTMENT NON-PHYSICIAN VISITS

Variable	B	SEB	t	p≤ t
Groups:				
CF	-0.18811	0.251763	-0.75	0.4551
Healthy	-0.57999	0.228275	-2.54	0.0112
SCD	ref			
Age	0.000305	6.32E-05	4.83	<.0001
Gender:				
Female	-0.01245	0.002091	-5.96	<.0001
Male	ref			
Ethnicity:				
Hispanic	-0.00513	0.001616	-3.17	0.0015
Black (Not Hispanic)	-0.00642	0.001838	-3.5	0.0005
Asian (Not Hispanic)	-0.00095	0.002531	-0.38	0.706
White/Other Race (Not Hispanic)	ref			
Education	0.000373	0.000177	2.11	0.0354
Insured				
No	-0.00607	0.001194	-5.08	<.0001
Yes	ref			
Intercept	0.587896	0.22806	2.58	0.0101

TABLE 13

ESTIMATED REGRESSION COEFFICIENTS FOR TOTAL OUTPATIENT DEPARTMENT PHYSICIAN VISITS

Variable	B	SEB	t	p≤ t
Groups:				
CF	0.099802	0.294714	0.34	0.7349
Healthy	-0.50528	0.150174	-3.36	0.0008
SCD	ref			
Age	4.12E-05	6.5E-05	0.63	0.5263
Gender:				
Female	-1E-05	0.001992	-0.01	0.9959
Male	ref			
Ethnicity:				
Hispanic	-0.00271	0.002315	-1.17	0.2415
Black (Not Hispanic)	0.001845	0.002596	0.71	0.4775
Asian (Not Hispanic)	-0.00907	0.002758	-3.29	0.001
White/Other Race (Not Hispanic)	ref			
Education	-0.00053	0.000163	-3.25	0.0012
Insured				
No	-0.00354	0.001594	-2.22	0.0266
Yes	ref			
Intercept	0.517574	0.150066	3.45	0.0006

TABLE 14

ESTIMATED REGRESSION COEFFICIENTS FOR TOTAL OFFICE-BASED PROVIDER VISITS

Variable	B	SEB	t	p≤ t
Groups:				
CF	-2.32525	4.432937	-0.52	0.6
Healthy	-9.57413	4.25836	-2.25	0.0247
SCD	ref			
Age	-0.0025	0.00096	-2.6	0.0093
Gender:				
Female	-0.18331	0.026454	-6.93	<.0001
Male	ref			
Ethnicity:				
Hispanic	-0.19251	0.020944	-9.19	<.0001
Black (Not Hispanic)	-0.18752	0.024349	-7.7	<.0001
Asian (Not Hispanic)	-0.15115	0.023909	-6.32	<.0001
White/Other Race (Not Hispanic)	ref			
Education	-0.011	0.001972	-5.58	<.0001
Insured				
No	-0.26365	0.014507	-18.17	<.0001
Yes	ref			
Intercept	10.40004	4.239929	2.45	0.0143

TABLE 15

ESTIMATED REGRESSION COEFFICIENTS FOR TOTAL OFFICE-BASED PHYSICIAN VISITS

Variable	B	SEB	t	p≤ t
Groups:				
CF	0.388728	1.601791	0.24	0.8083
Healthy	-5.4238	1.264322	-4.29	<.0001
SCD	ref			
Age	-0.00425	0.000449	-9.48	<.0001
Gender:				
Female	-0.12491	0.014741	-8.47	<.0001
Male	ref			
Ethnicity:				
Hispanic	-0.11427	0.016127	-7.09	<.0001
Black (Not Hispanic)	-0.1048	0.018099	-5.79	<.0001
Asian (Not Hispanic)	-0.1063	0.018172	-5.85	<.0001
White/Other Race (Not Hispanic)	ref			
Education	-0.01293	0.001201	-10.76	<.0001
Insured				
No	-0.19865	0.009709	-20.46	<.0001
Yes	ref			
Intercept	6.119447	1.262209	4.85	<.0001

TABLE 16

ESTIMATED REGRESSION COEFFICIENTS FOR TOTAL HOSPITAL DISCHARGES

Variable	B	SEB	t	p≤ t
Groups:				
CF	0.223257	0.400162	0.56	0.577
Healthy	-0.3604	0.100446	-3.59	0.0003
SCD	ref			
Age	-0.00011	4.1E-05	-2.63	0.0086
Gender:				
Female	-0.00163	0.001169	-1.4	0.1625
Male	ref			
Ethnicity:				
Hispanic	-0.00153	0.001035	-1.48	0.1403
Black (Not Hispanic)	-0.00032	0.001197	-0.26	0.7925
Asian (Not Hispanic)	-0.00379	0.002513	-1.51	0.1315
White/Other Race (Not Hispanic)	ref			
Education	-9.6E-05	0.000157	-0.61	0.5402
Insured				
No	0.000536	0.000947	0.57	0.5719
Yes	ref			
Intercept	0.368065	0.100288	3.67	0.0003

TABLE 17

ESTIMATED REGRESSION COEFFICIENTS FOR TOTAL NIGHTS IN HOSPITAL FOR DISCHARGES

Variable	B	SEB	t	p≤ t
Groups:				
CF	1.214825	2.481842	0.49	0.6246
Healthy	-1.66491	0.493837	-3.37	0.0008
SCD	ref			
Age	-0.00055	0.000265	-2.05	0.0401
Gender:				
Female	-0.00463	0.008012	-0.58	0.5632
Male	ref			
Ethnicity:				
Hispanic	-0.00505	0.008757	-0.58	0.5639
Black (Not Hispanic)	-0.00237	0.010093	-0.23	0.8145
Asian (Not Hispanic)	-0.02504	0.01603	-1.56	0.1186
White/Other Race (Not Hispanic)	ref			
Education	-0.00022	0.001065	-0.2	0.8393
Insured				
No	-8.3E-05	0.005032	-0.02	0.9868
Yes	ref			
Intercept	1.701851	0.493704	3.45	0.0006

CHAPTER 5

DISCUSSION

The goal of this thesis project was to describe the direct and indirect costs to SCD patients and compare these costs to a comparable chronic disease, specifically CF. Due to low research funding that in turn plays a role in public outreach, this study was another way of showing the high medical expenditures trends for SCD in relation to the widening gap in funding. My findings are consistent with existing literature demonstrating higher than average medical expenditures for SCD patients. This study differs from previous research in that it uses nationally representative MEPS data to describe the non-institutionalized, U.S. SCD population as well as medical expenditures over time, and it provides a direct comparison with another patient population.

The research question addressed in this study was whether there was a difference between the SCD and CF patient populations in terms of cost and health status measures. CF patients had higher number of prescription medications and higher medication expenses when compared with SCD patients. There were no other significant differences between the SCD and CF patient populations in terms of cost and health status measures. These results are meaningful as they demonstrate that SCD patient and CF patient health status are not significantly different after controlling for the dramatic differences in the demographics of the patient population. Also, this study compliments research stating that SCD patients have significantly higher medical costs and personal costs when compared to persons with no medical conditions. These results validate the need for more research into medical care and medical expenditures for SCD patients; health care should be cost-effective without loss of quality. Currently, SCD is underfunded in terms of research support in comparison to CF

when the relative sizes of the patient populations are taken into account. This is especially problematic when it has been demonstrated that for almost all measures of costs and health status, the two disease populations are comparable. The only way to increase high quality research is to increase funding as well as increase awareness, it is clear that both go hand in hand. Without proper funding, private organizations are less than able to adequately educate the general public and advocate for better treatment as well as dispel stigmas associated with diseases.

Limitations

A noticeable limitation is that comparisons were based on a small absolute number of respondents for the SCD and CF population (79 versus 43, respectively). However the population-level estimates for the SCD and CF populations (102,469 versus 88,428, respectively) are comparable to what is known about both patient populations. For instance, the predominant ethnicity for the sickle cell disease population was consistent with what is known about the ethnicity that is widely affected by sickle cell anemia.

Another disadvantage of MEPS data is that subjects are only followed for a period of two years, which limits the ability to look for trends over time within individuals. Despite these limitations, MEPS is still a good fit as a data source for this study because of the lack of SCD research using large-scale survey data, the free access to the MEPS data, and the national representation of the survey.

The biggest limitation of the target population and use of the MEPS datasets is the way that sickle cell anemia disease is classified. In order for the data to be publicly available, it has to be de-identified; any variable that can be used to easily identify a survey participant has been removed. This de-identification also means that International Classification of

Diseases, Ninth Revision, Clinical Modification (ICD-9) codes, are provided at the 3-digit level in order to prevent identification of specific diagnoses at the most precise level. The International Classification of Diseases, Ninth Revision, Clinical Modification is used by the U.S. as the official system to classify and code health conditions and the like. The raw 5-digit level ICD-9 data have been grouped into clinical classification codes (CCC) in order to provide grouped diagnosis data without providing the detail that might risk identification of individuals. Clinical Classification Software (formerly known as Clinical Classifications for Health Care Policy Research is used to group clinically homogeneous conditions into categories. The CCC for sickle cell anemia disease is 61, which includes the following ICD-9-CM codes: 28241, 28242, 2825, 28260, 28261, 28262, 28263, 28264, 28268, and 28269. Therefore, respondents with any of the following conditions are grouped together: sickle-cell thalassemia without crisis, sickle-cell thalassemia with crisis, sickle-cell trait (SCT), sickle-cell anemia, Hb-SS disease without mention of crisis, Hb-SS disease with mention of crisis, Hb-S/Hb-C disease without crisis, Hb-S/Hb-C disease with crisis, other sickle-cell disease with crisis, and other sickle-cell disease without crisis. In general, all of the above conditions are considered 'sickle cell anemia' except for sickle cell trait (ICD-9-CM: 2825). Typically, when SCD is studied, patients characterized as having one normal hemoglobin and one sickle hemoglobin are not included in the target population. This resulted in a conservative estimate of the impact of SCD in terms of costs and health status since the patient population undoubtedly included a proportion of people who had sickle cell trait rather than sickle cell disease. While researchers are still trying to determine if sickle cell trait carriers have any complications, sickle cell trait is not sickle cell anemia disease; most SCT carriers go on to have normal, healthy lives.[8] This inclusion in the target population for this study could have

skewed the results in the direction of underestimating estimations of the impact of the disease, especially when looking at the health status variables. Given the time and cost limitations of this study, however, it was not possible to determine which patients had an actual ICD-9-CM code of 2825 and exclude them.

Conclusion

With no cure for SCD and high medical costs, patients are urged to take preventive measures when it comes to the management of their disease. Doctors and research recommend daily lifestyle changes like increased hydration, sufficient rest, adequate warmth, regular physical examinations, and avoidance of excessive heat, exercise, cold, altitude, and crowd exposure.[8,15-21] These recommendations serve as a burden to the SCD patient in terms of costs and limitations to functioning. If there is to be a cure found, more research is needed. The need for support of SCD research through federal funding is necessary. While some private organizations have been able to educate the public, support patients and their families, as well as improve research efforts through funding, the successes of some organizations further the disparities between diseases. While it would be great for SCD to receive more private funding so as to minimize the gap, it is unrealistic given the socio-economic status of many of those affected by SCD. Using SCD and CF as examples, it is clear to see that private funding is not always associated with disease prevalence. The government has the role of decreasing the funding gap between diseases as well as making sure all funding is based on the burden of the disease as indicated by markers such as total mortality, years of life lost, incidence, prevalence, disability.[33]

Research for improved treatments and cures continue to be underfunded and overlooked and the patients are the ones who suffer from inadequate access to research. SCD

is not the only underfunded disease but can be looked upon as an example of the devastating results that come from insufficient research due to the severity of the disease and the population it affects. It is possible for all conditions to have new therapies and developments if there is a commitment to equity in funding resources. Diseases, such as SCD, should no longer be allowed to go on underfunded with the disparities staring researchers in the face.

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VITA

Victoria Nkem Ojo was born on August 3, 1987, in Kansas City, Missouri. She was educated in local public schools and graduated from Blue Valley West High School with honors in 2005. She received a George C. Brooks Scholarship to the University of Missouri in Columbia, Missouri, and later transferred to University of Missouri in Kansas City, from which she graduated in 2009. Her degree was a Bachelor of Science in Chemistry, an American Chemical Society approved degree program.

After working as a specimen management associate for five months at Quintiles in Overland Park, Kansas, Ms. Ojo began a master's program in bioinformatics at the University of Missouri-Kansas City.

Upon completion of her degree requirements, Ms. Ojo plans to continue her career in chemistry and bioinformatics and to pursue research interests.