Achieving a Better Understanding of the Impact of Sickle Cell in Indiana

2017 CHeP Pilot Project Symposium

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Primary Aims of Project

- Obtain much-needed estimates of the prevalence of sickle cell disease (SCD) in central Indiana
- Describe health care costs for patients with SCD in central Indiana

Primary Aims of Project

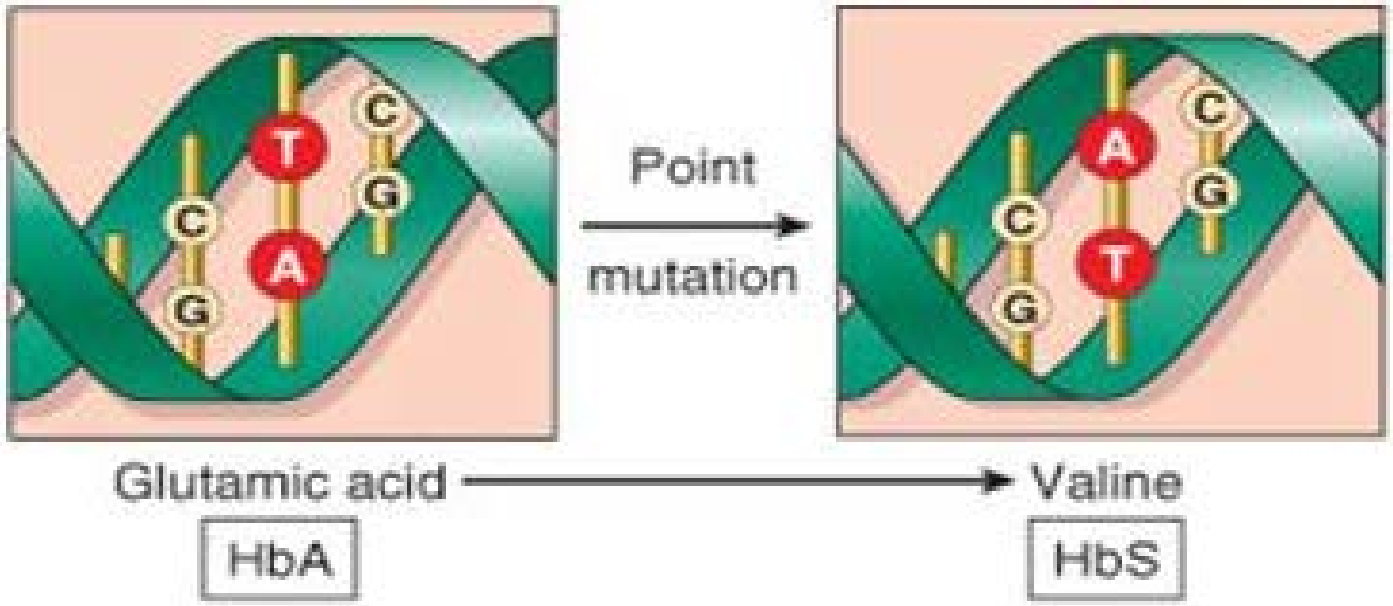
- Develop a sustainable partnership among the following entities:
  - Indiana Children's Health Service Research
    - Section of the Department of Pediatrics at Indiana University Health that strives to improve the healthcare of children research and informatics
  - Martin Center Sickle Cell Initiative
    - Non-profit human services agency that aids and enhances the lives of those affected by sickle cell via services, education, and public advocacy

Secondary Aims of Project

- Determine if the impact of SCD on the affected population is burdensome from a financial standpoint
- Determine if the impact of SCD on the health care system is disproportionately high when compared to that of healthy people
- Determine the impact of SCD on public insurance (aka Medicaid)

Sickle Cell Disease (SCD) Definition

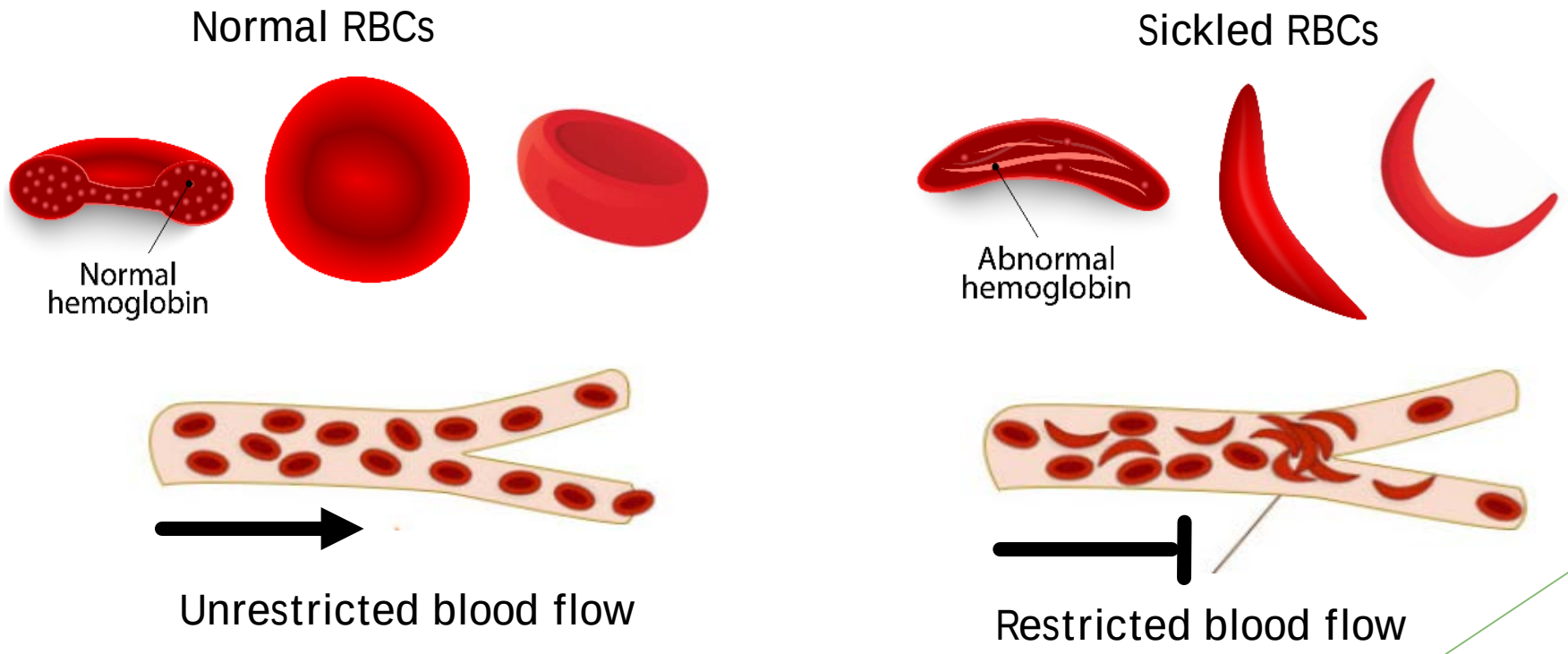
- Abnormal hemoglobin within the red blood cell (RBC) due to amino acid substitution at position 6 within the beta globin gene



Google Images. Pathophysiology of sickle cell disease. Elsevier 2005.

SCD Significance

- RBCs become crescent-moon shaped (versus biconcave) and are no longer deformable, leading to a shortened lifespan of 20 days (versus 120 days) and persistent anemia



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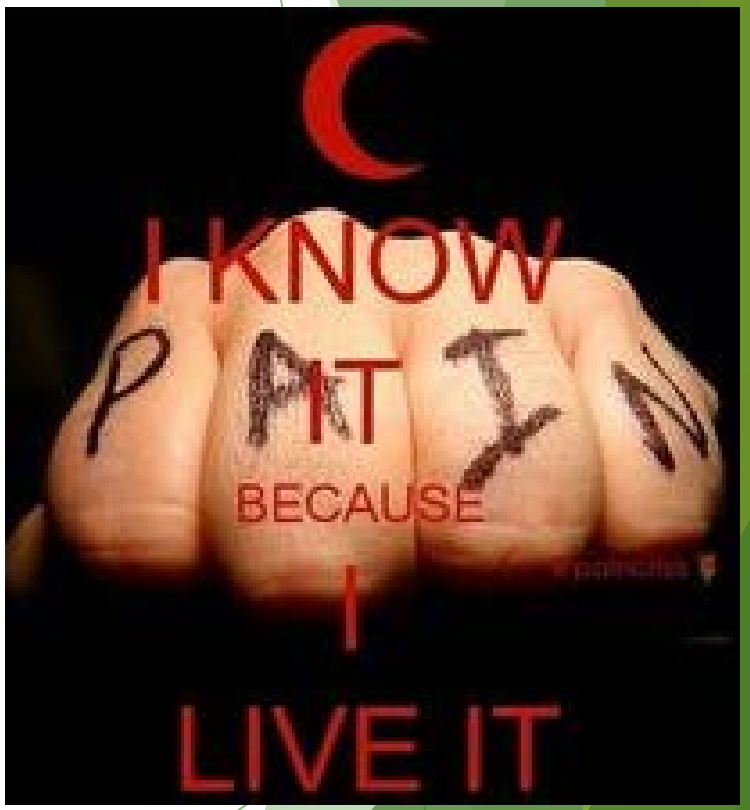
SCD Manifestations

- Hallmark: pain
  - Most common clinical manifestation resulting in severe suffering of prolonged absences from school and difficulties maintaining full employment
- Unpredictable onset and duration
  - Presents as sudden severe deep pain with or without a trigger
  - Any body part affected
  - Duration lasts hours to weeks
- Symptomatic relief: narcotics



American Society of Hematology. State of Sickle Cell Disease. Introduction, page 2.

Google Images. Pininterest.com

SCD Manifestations

- Subjective
  - No tests or validated biomarkers to rule in or rule out; tests that only potentially rule out other causes
- Innocent symptoms may be a red flag for severe a complication
  - Headache → Stroke
  - Chest pain → Acute chest syndrome
  - Flank pain → Papillary necrosis
  - Abdominal pain → Hepatic sequestration

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SCD Global Epidemiology

- SCD affects ~300,000 births annually
- SCD is the most prevalent in malaria endemic parts of the world
- 10-40% of the population in African countries carries the sickle cell gene, resulting in an estimated SCD prevalence of at least 2%
- Global management of SCD is similar to in the US before 1970
  - SCD remains a significant killer of infants and children, similar to that of malaria and HIV/AIDS.
- By 2025, the number of those with SCD is expected to increase by 30%

Centers for Disease Control and Prevention. World Health Organization. Piel et al 2013. Lancet 381:142-51.

American Society of Hematology. State of Sickle Cell Disease. Introduction, page 2

SCD US Epidemiology

- Sickle cell disease
  - Prevalence: >100,000 people
  - Incidence: ~1 in 350 African-American births and ~1 in 16,300 Hispanic-American births
- Sickle cell trait
  - Incidence: ~1 in 10 African-American births

Centers for Disease Control and Prevention. World Health Organization. Piel et al 2013. Lancet 381:142-51.

Did You Know?

- The World Health Organization and United Nations recognize SCD as a global health issue.
- Individuals with SCD in the ED for pain treatment experience **longer** delays to administration of the initial analgesic compared with control patients, despite **higher** pain scores and triage acuity upon ED arrival.
- SCD is also associated with high treatment costs. Assuming that the average individual with SCD lives until age 45 years, total lifetime health care costs are ~$1 million. Annual costs range from >$10k for children to >$30k for adults.

American Society of Hematology. State of Sickle Cell Disease. Introduction, page 8.

Matthew P. Lazio et al. A Comparison of Analgesic Management for Emergency Department Patients with Sickle Cell Disease and Renal Colic. Clinical Journal of Pain 2010, 26(3):199-205.

Methods

- Study approved by Institutional Review Board
- Data extraction based on ICD-9-CM and ICD-10-CM codes specific to sickle cell at any Indiana University Health facility were eligible for inclusion
  - No human subject interactions
- Time period: 5 years from 7/1/11 to 6/30/16
- Pediatric data: Individuals ≤21 years of age
- Unit of analysis: Patient encounter

Challenges

- Accessibility to data
- Vague data
  - Inability to distinguish location of service: ED vs clinic vs infusion center
- Inconsistent and non-specific diagnostic coding methods
- Lack of baseline studies for comparative purposes

Health Care Costs for Pediatric Patients with Sickle Cell Disease in Indiana

Health Care Costs for Pediatric Patients with Sickle Cell Disease in Indiana

$4,024,929

Baseline demographics and clinical characteristics

Demographic/Characteristic	Number (% of total, if applicable)
Unique patient encounters	428
Age at service (years)	
0-5	136 (32%)
>5-10	107 (25%)
>10-15	98 (23%)
>15-21	87 (20%)
Gender	
Male	242 (56%)
Female	186 (44%)
Sickle cell disease genotype	
Hb SS	236 (55%)
Hb SC	73 (17%)
Hb $S\beta^0$ or Hb $S\beta^+$	40 (9%)
Unspecified	79 (19%)

Baseline demographics and clinical characteristics

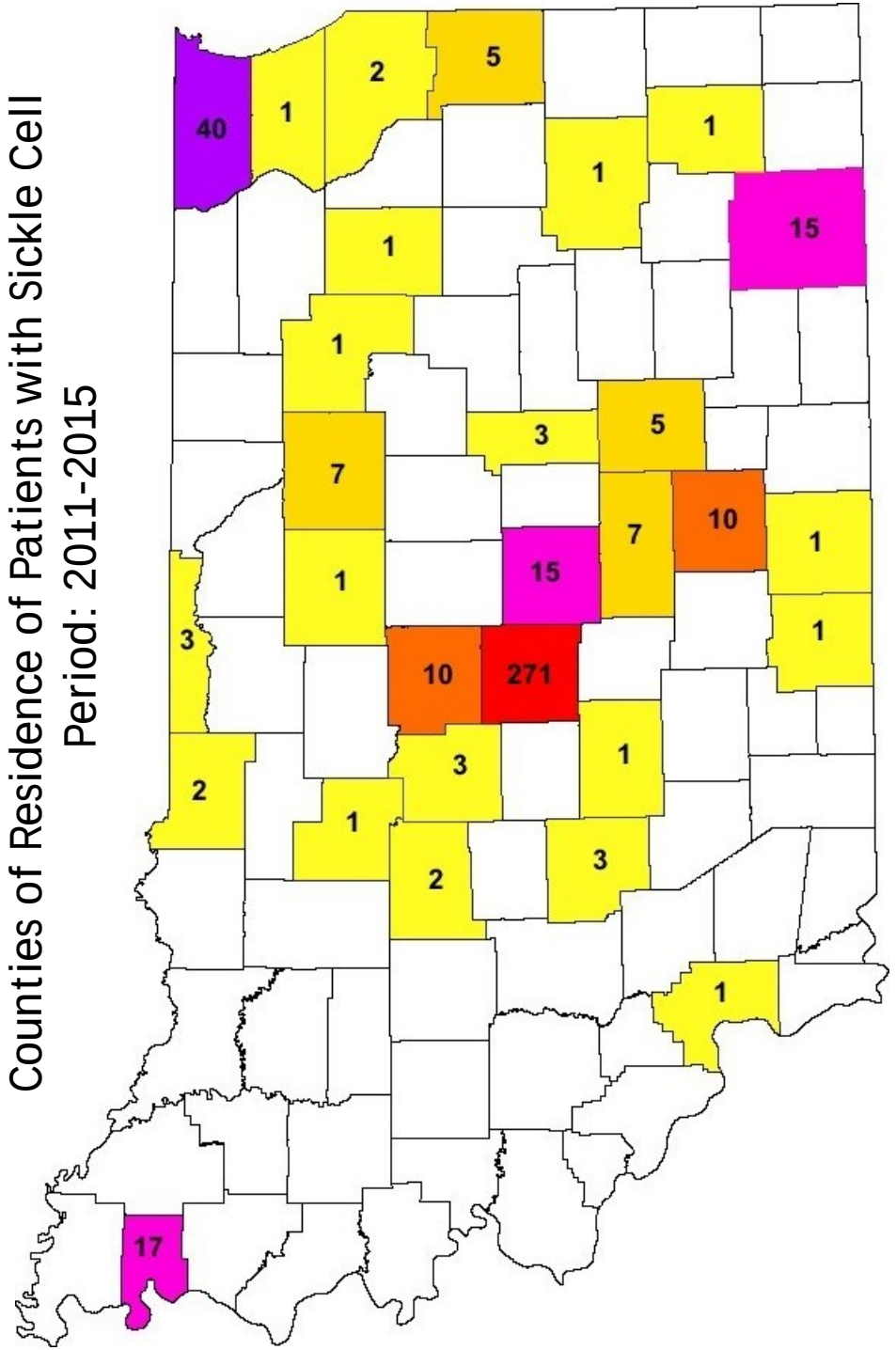
Demographic/Characteristic	Number (% of total, if applicable)
Unique patient encounters	428
Race	
Black	415 (97%)
White (Hispanic)	3 (<1%)
Asian	1 (<1%)
Multiracial/Other	4 (<1%)
Unknown	5 (1%)
Ethnicity	
Non-Hispanic	417 (98%)
Hispanic	1 (<1%)
Unknown	10 (2%)

Baseline demographics and clinical characteristics

Demographic/Characteristic	Number (% of total, if applicable)
Unique patient encounters	428
Payer source	
Public insurance	318 (74%)
Private insurance	83 (19%)
Both public and private insurance	2 (<1%)
Uninsured	17 (4%)
Unknown	8 (2%)

Baseline demographics and clinical characteristics

Demographic/Characteristic	(% of total, if applicable)
Unique patient encounters	428
Region of residence	
Northwest	50 (12%)
Northeast	17 (4%)
Central	338 (79%)
Southwest	19 (4%)
Southeast	4 (1%)



Components of Health Care Costs for Pediatric Patients with SCD in Indiana

Location of Service	**Costs (% of total)**
Inpatient	$2,521,634 (63%)
Outpatient	$1,503,295 (37%)
Total	$4,024,929

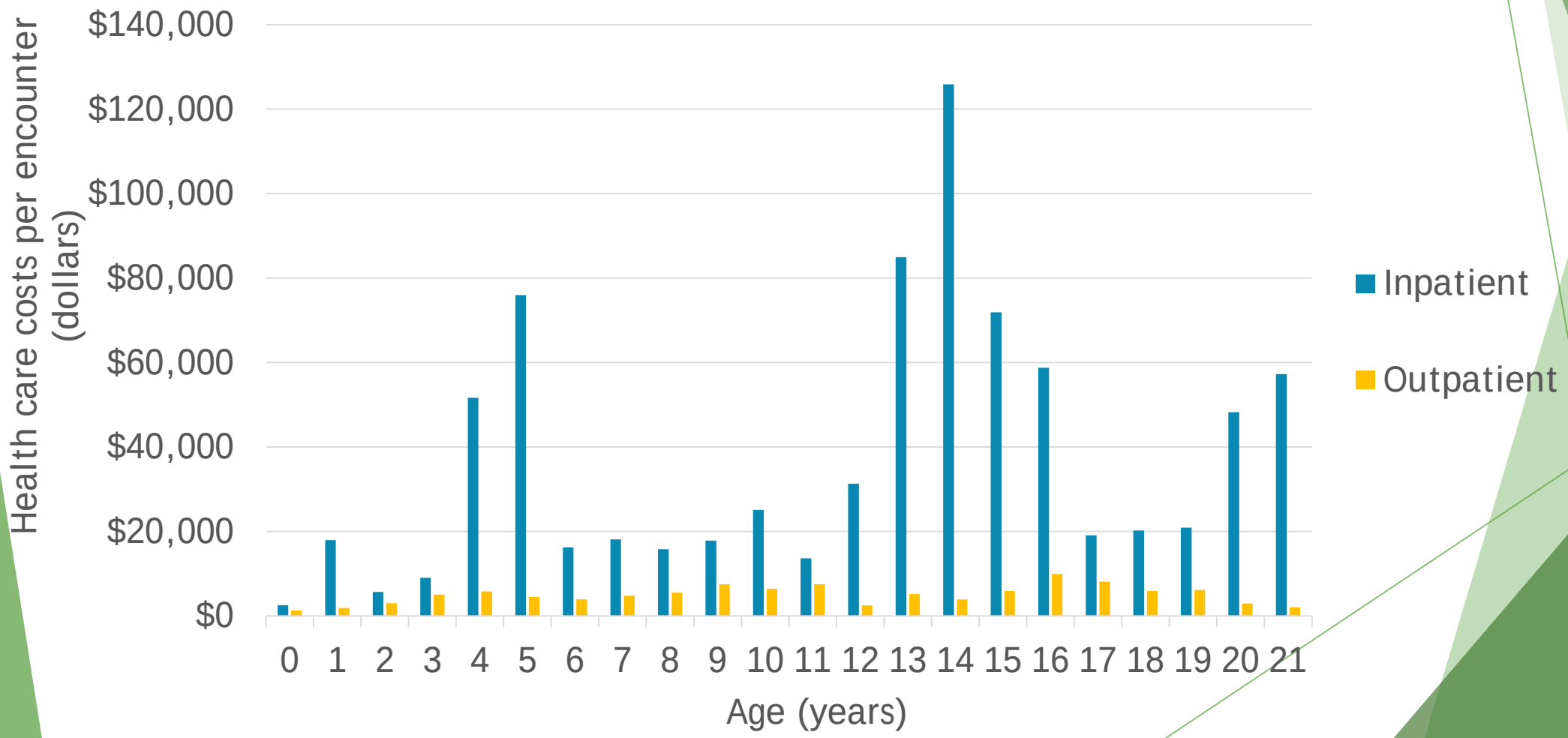
Health Care Costs for Pediatric Patients 0-10 years with SCD in Indiana

	Outpatient		Inpatient	
Age (years)	Cost per encounter	Number of encounters	Cost per encounter	Number of encounters
0	$1,289	26	$2,508	4
1	$1,876	29	$17,939	3
2	$2,983	18	$5,638	5
3	$5,063	10	$9,043	4
4	$5,754	15	$51,660	7
5	$4,448	17	$75,946	1
6	$3,882	21	$16,245	6
7	$4,741	21	$18,111	4
8	$5,491	17	$15,800	5
9	$7,484	13	$17,824	4
10	$6,377	16	$25,081	3

Health Care Costs for Pediatric Patients 11-21 years with SCD in Indiana

	Outpatient		Inpatient	
Age (years)	Cost per encounter	Number of encounters	Cost per encounter	Number of encounters
11	$7,493	14	$13,597	7
12	$2,450	27	$31,302	4
13	$5,124	11	$84,944	2
14	$3,897	15	$125,877	1
15	$5,890	12	$71,857	2
16	$9,940	10	$58,730	2
17	$8,111	9	$19,084	9
18	$5,886	9	$20,188	12
19	$6,098	9	$20,895	8
20	$2,916	9	$48,220	3
21	$2,049	6	$57,249	1

Health Care Costs per Encounter for Pediatric Patients 0-21 years with SCD in Indiana



Conclusions

- Majority of health care expenditures for SCD in central Indiana occurred in the inpatient setting while the majority of patient encounters occurred in the outpatient setting.
- There seems to be an upward trend in inpatient costs with increased age, consistent with Kauf et al.
  - SCD pathophysiology worsens over time.
- Public funds (Medicaid) are the primary payer source for health costs, which parallels the findings in the national statistical brief spanning from 1994 to 2004.
- Findings suggest that decreased hospitalization will ease the economic tax burden for sickle cell health costs.

Recommendations to Healthcare Policy Makers

- Provide more resources to support comprehensive sickle cell education for both providers and patients.
  - Recognize psycho-social challenges that contribute to and/or affect the overall health of patients with sickle cell.
  - Assist providers in counseling patients about the clinical and economic consequences.
- Develop and implement more preventative and curative therapies in the outpatient setting to minimize emergency department utilizations and hospitalizations.
  - Prioritize research efforts
- Utilize information to better plan for future economic needs of patients.


PEACE
LOVE
CURE
Sickle Cell Disease