



## Health status, functional limitations, and health care utilization among US children with sickle cell disease

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### Presenter Disclosures: Sheree Boulet

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

**No relationships to disclose**



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### Introduction

- Children with sickle cell disease (SCD) often require multiple long term medical treatments for complications such as hemolytic anemia, pain crises, and bacterial infections
- Findings from some studies also suggest SCD may be associated with cognitive effects including deficits in attention and executive functions, memory, language, hearing, and academic achievement



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### Introduction (2)

- Population-based studies on health and functional status, health care use, and access to care for children with SCD are lacking
  - Findings from available studies indicate that low-income children with SCD had higher rates of hospitalization, ED visits and home health care than children without SCD
  - Limited information on the overall scope and prevalence of co-morbidities for children with SCD and how these factors impact the health burden for children and families



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### Study Aim

- To describe health status and health services use in a nationally representative population of non-Hispanic black children with and without SCD



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### Objectives

- 1) Estimate the prevalence of co-occurring medical and developmental conditions
- 2) Examine indicators of functional status and perceived health status
- 3) Assess use of health care services
- 4) Evaluate barriers to accessing health services



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### Study Population

- Data were derived from 1998-2005 National Health Interview Survey (NHIS)
  - Multistage probability sample survey of US households conducted annually
  - One child <18 years of age is randomly selected from each family with children and information pertaining to that child is collected via the Sample Child Core questionnaire
- Final sample composed of children 0-17 years who participated in questionnaire and whose race was reported as non-Hispanic black



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### SCD

- SCD ascertained from the question: “Has a doctor or other health professional ever told you that [child’s name] had sickle cell anemia?”
- Unweighted sample consisted of 169 non-Hispanic black children with SCD and 16,300 without SCD
  - Weighted sample: 108,681 and 9,712,109, respectively



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### Co-occurring Conditions

- Medical conditions during the 12 months prior to the interview: anemia, asthma attack, hay fever, respiratory allergy, food or digestive allergy, eczema or skin allergy, frequent diarrhea or colitis, frequent severe headaches or migraines, and  $\geq 3$  ear infections
- Developmental conditions: ADD/ADHD (2-17 years), learning disability (3-17 years), mental retardation, trouble hearing, trouble seeing, and other developmental delay



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### Health Impact and Service Use

- Health impact was examined via a series of questions addressing functional limitations and report of child's current health status
- Health care use during past 12 months was evaluated by types of providers seen and frequency of visits to doctor's office and to a hospital ED
- Also assessed delays in receiving medical care in past 12 months



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### Statistical analysis

- All estimates and standard errors were weighted to reflect the national noninstitutionalized population of US non-Hispanic black children 0-17 years of age
- We assessed differences between children with SCD and those without in the proportions of concurrent medical and developmental conditions, health care utilization, and barriers to accessing care with chi-square tests and odds ratios from multivariable logistic regression models
  - Covariates included child sex, age, maternal education, household income, health insurance status, region of residence, and year of survey



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### Demographic characteristics of non-Hispanic black children with and without SCD, 1998-2005

Characteristic	SCD	No SCD
	Weighted %	Weighted %
<b>Child sex</b>		
Male	56.5	50.6
Female	43.5	49.4
<b>Child age (years)</b>		
<3	17.2	16.0
3-5	12.2	15.9
6-10	28.5	28.2
11-17	42.0	39.9
<b>Maternal education</b>		
<HS	24.0	18.6
HS/GED	35.8	32.8
>HS	40.2	48.7



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### Demographic characteristics of non-Hispanic black children with and without SCD, 1998-2005

Characteristic	No SCD	
	Weighted %	Weighted %
<b>Household Income (% FPL)</b>		
<100%	46.2*	34.0
100-200%	23.9	26.2
>=200%	29.9	39.7
<b>Insurance</b>		
Medicaid/SCHIP	53.4*	39.2
Private	33.3	45.7
Other	4.9	5.0
None	8.4	10.0
<b>Region</b>		
Northeast	7.4*	16.2
Midwest	24.0	20.5
South	60.5	55.3
West	8.2	8.1



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### Medical conditions among NHB children with and without SCD, 1998-2005

Condition	SCD		No SCD	
	Weighted %	Weighted %	AOR**	95% CI
<b>Anemia</b>	12.8*	1.8	8.4	4.6-15.2
<b>Asthma</b>	6.2	7.6	0.8	0.4-1.5
<b>Hay fever</b>	12.3	8.6	1.4	0.8-2.5
<b>Respiratory allergy</b>	11.8	10.9	1.0	0.6-1.7
<b>Food/digestive allergy</b>	5.2	3.4	1.9	0.8-4.2
<b>Eczema/skin allergy</b>	12.9	10.8	1.2	0.7-2.1
<b>Frequent diarrhea/colitis</b>	3.4	1.5	2.5	0.9-6.7
<b>Frequent severe headaches/migraines</b>	17.3*	6.8	2.6	1.4-5.0
<b>&gt;=3 ear infections</b>	8.7	4.7	1.6	0.6-6.4



\* P<.05; \*\* Adjusted for year of survey, sex, age, maternal education, household income, health insurance status, and region of residence

### Developmental conditions among NHB children with and without SCD, 1998-2005

Condition	SCD		No SCD	
	Weighted %	Weighted %	AOR**	95% CI
<b>ADD/ADHD (ages 2-17 only)</b>	6.6	5.8	0.8	0.3-1.8
<b>Hearing impairment</b>	5.3	2.8	1.9	0.9-4.2
<b>Learning disability (ages 3-17 only)</b>	12.5	8.9	0.9	0.5-1.9
<b>Mental retardation</b>	3.1*	0.6	3.8	1.3-11.0
<b>Vision impairment</b>	6.4	2.3	2.0	0.8-4.9
<b>Other developmental delay</b>	4.5	3.2	1.5	0.7-3.4



\* P<.05; \*\* Adjusted for year of survey, sex, age, maternal education, household income, health insurance status, and region of residence

### Health and functional status of NHB children with and without SCD, 1998-2005

Condition	SCD		No SCD	
	Weighted %	Weighted %	AOR**	95% CI
<b>Limited in ability to crawl, walk, run, or play (lasting ≥12 mos)?</b>	7.0*	1.9	3.8	1.8-8.0
<b>Needs special equipment (e.g. brace or wheelchair)</b>	3.6	0.8	2.6	0.7-9.2
<b>Regularly taken prescription meds for &gt;3 months</b>	32.5*	11.3	3.2	2.0-5.2
<b>Health status fair or poor</b>	12.9*	3.3	4.3	2.3-8.1



\* P<.05; \*\* Adjusted for year of survey, sex, age, maternal education, household income, health insurance status, and region of residence

### Health services use among NHB children with and without SCD, 1998-2005

	SCD		No SCD	
	Weighted %	Weighted %	AOR**	95% CI
Seen medical specialist	24.8*	8.7	3.4	2.1-5.4
Seen mental health professional	10.3	5.4	1.9	0.9-4.0
Seen physical, speech, respiratory, or occupational therapist	9.8	4.7	1.8	0.9-3.8
>9 office visits	11.2*	5.0	2.5	1.3-4.9
>1 emergency visit	46.5*	23.7	3.1	1.9-4.8
Had surgery or medical procedure	5.6	3.4	1.8	0.8-3.8

\* P<.05; \*\* Adjusted for year of survey, sex, age, maternal education, household income, health insurance status, and region of residence



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### Health care barriers among NHB children with and without SCD, 1998-2005

	SCD		No SCD	
	Weighted %	Weighted %	AOR**	95% CI
Could not get through on phone	5.0	1.8	2.1	0.9-5.1
Could not get appointment soon enough	10.6*	3.8	2.6	1.3-5.2
Waited too long in doctor's office	9.2	3.8	2.6	1.2-5.6
No transportation	5.8	3.0	1.3	0.5-3.4
Could not afford prescription meds	5.2	3.9	1.2	0.5-2.8

\* P<.05; \*\* Adjusted for year of survey, sex, age, maternal education, household income, health insurance status, and region of residence



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### Summary

- SCD was independently associated with mental retardation, mobility limitations, and poor overall health status.
- Children with SCD were approximately 3 times more likely than children without SCD to have seen a medical specialist and to have >9 office visits and >1 ED visit in the past year.
  - Odds of having seen a mental health professional and therapist approached statistical significance



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### Summary (2)

- Parents of children with SCD encountered more challenges in accessing health care than parents of children without SCD
  - Difficulty getting through on phone , scheduling appointments, and long waits at doctor's offices



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### Limitations

- SCD was ascertained by parent report
  - No information on SCD genotypes or history of stroke
- Medical and developmental conditions and health service use were based on parent report
- Assessment of medical conditions limited to recent episodes and overt conditions
- Unable to assess use of special services relevant to children with SCD
- High variability for some point estimates



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### Conclusions

- Our findings highlight the association between SCD, risk for co-morbid medical and developmental conditions, and use of health services
  - Underscore importance of screening for cognitive, hearing, and vision deficits
- Results suggest that that children with SCD have a disproportionate amount of difficulty in accessing necessary health care services



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### Future Research

- Impact of socioeconomic condition, related stressors, and disease process
- Further studies are needed to explore the extent of unmet health needs for children with SCD and the interaction between unmet needs, family functioning, and long term health outcomes



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