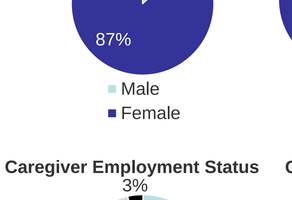
Older female children experience poorer quality of life when levels of perceived racial bias are high

Anna Hood, PhD, Lori Crosby, PsyD, Jeff Lesenburger, MD, Avi-Madan Swain, PhD, Deanna Rumble, PhD, Zina Trost, PhD

Introduction

Sickle cell disease (SCD) is an inherited red blood disorder that primarily effects individuals of African Ancestry. There are approximately 100,000 Americans with SCD, of whom 40% are children. There are various types of SCD, but hemoglobin SS (HbSS) is the most common form[3].
SCD causes the hemoglobin of red blood cells to change into a “sickle shape” instead of the usual disc shape.

These blood cells then get stuck in the bloodstream and makes the healthy cells unable to travel and carry oxygen to different areas of the body.



Individuals with sickle cell disease (SCD) experience significant health problems that result in unpredictable pain episodes and frequent healthcare utilization. Disparities in clinical care and emergency room visits in which medical providers mistrust the severity of reported pain symptoms may contribute to health-related stigma.

In addition to stigma related to seeking care for acute pain, racism is a source of stigma with associated systemic inequities for this majority Black population. There is currently limited research into the effects of health-related stigma and racial bias on the underserved SCD population; however, the small body of research has found barriers to healthcare utilization, greater pain burden, and increased emotional distress.

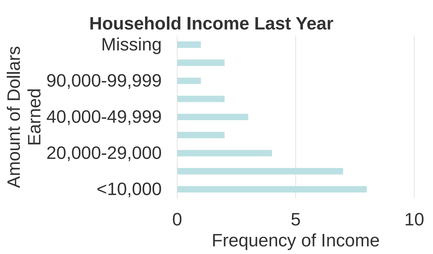
Study Goals:

- There is little known about the influence of health-related stigma and racial bias on quality of life (QOL) of children with SCD. The present study assessed these relationships, and additionally, we sought to understand whether there were differences in this relationship with regards to demographic factors (e.g., age, gender).

Demographics

Table 1. Characteristics of Children with SCD and their Caregivers

	Child	Caregiver
Age Mean (SD)	11.3 (2.73)	38.21 (7.67)
Race		
African-American	100%	96.7%
Genotype		
HbSS	63%	--
HbSC	23%	--
HbSB+ Thalassemia	10%	--
Not reported	1%	--



Methods

Participants were a convenience sample children with SCD ages 8-16 and their caregivers from a large medical center in the Southern United States. Caregivers provided demographic information.

Participants completed:

- **Health-related Stigma**. Childhood Stigma Scale (adapted for SCD), is an 8-item scale that measures perceived stigma in children with SCD.
- **Perceived Racism**. the Child Perceptions of Racism in Children and Youth scale (PRaCY), a 10-item scale that assesses whether children have felt discriminated against because of the color of their skin, language or accent, or because of your culture or country of origin.
- **Quality of Life.** The Peds QL Sickle Cell Disease is a 43 item module that assesses health-related quality of life for children with SCD. Higher scores indicate better quality of life

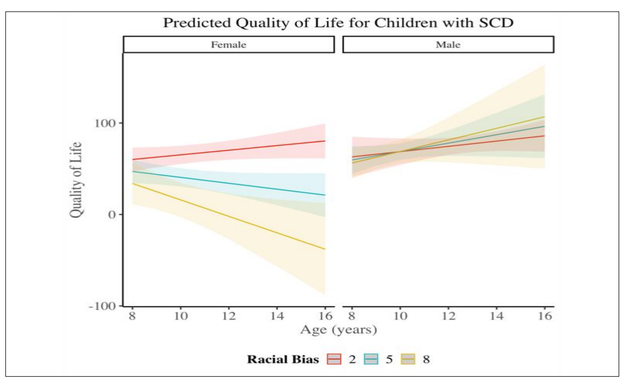
Results

Table 2. Scores for children with SCD and their caregivers on measures of stigma, perceived racism, and quality of life.

Scales	Child Mean (SD) Range
Stigma Range	3.6 (2.77) 0 – 8
Perceived Racism Range	2.2 (1.2) 1 – 5
Quality of Life Range	64.0 (20.9) 24 – 99

We first assessed whether age, gender, and health-related stigma predicted QOL and demonstrated a significant overall model, $F(7, 22) = 4.59$, $p = .003$, $r = .46$. Health-related stigma ($p = .007$) predicted QOL, but neither age or gender were significant predictors. The next model assessed whether age, gender, and racial bias predicted QOL and demonstrated a significant overall model, $F(7, 22) = 4.59$, $p < .001$, $r = .52$. Specifically, age ($p = .03$), but neither gender or racial bias were significant predictors.

Figure 1. Predicted QOL for children with SCD



Of interest, there was significant interaction between age, gender, and racial bias (p = .02), which indicated that males generally had higher QOL that did not differ as a function of racial bias or age. Similarly, females who reported low levels of racial bias had higher QOL that did not differ as a function of age. In contrast, females who reported high levels of racial bias had QOL that differed as a function of age. Specifically, older female children who reported high levels of perceived racial bias had poorer QOL.

Discussion

Health-related stigma is increasingly becoming a major public health issue that requires more focus to better understand the cause. The current study found that children with SCD reported high levels of health-related stigma and perceived racism in their daily lives.

In the current study, health-related stigma and perceived racism predicted quality of life. Of particular interest, the relationship between perceived racism and quality of life differed as a function of age and gender.

Specifically, older female children who reported high levels of perceived racial bias had poorer QOL.

Implications:
Our study highlights the need for increased awareness about the effects of health-related stigma and racial bias in children with SCD and demonstrates that older female children seem particularly affected by racial bias which negatively impacts their QOL. The findings provide new information that could influence the development of future interventions tailored to the specific needs of older female children with SCD.

Limitations:
Due to our sample size, we did not have the power to detect smaller effects. We also used short-form self-report methods. Interviews or following families over time would have added to our study and expanded our knowledge.

Future research should determine the relationship between quality of life, stigma, perceived racism. and pain. Moreover, we could next study the effectiveness of workshops developing the communication skills between physicians and patients. Further, research on the impact of teaching patients about their disease on their perceptions of stigma would provide additional clarity.

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