



Awareness of Sickle Cell Status among Adolescents and Caregivers in an Inner-City Community Hospital

PUBLISHED ABSTRACT

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ABSTRACT

Background: Despite universal newborn screening available in the United States, babies with sickle cell disease (SCD) are often born to parents who did not know they had sickle cell trait (SCT) before pregnancy. The objective of this study was to assess the knowledge of SCD and SCT among adolescents and their caregivers in our community.

Methods: It was a descriptive cross-sectional study. Self-administered anonymous questionnaires were distributed by convenient sampling method to adolescents and their caregivers in the general ambulatory and in-patient setting in an inner-city hospital. Multivariable adjusted logistic regression models were used to determine predictors of awareness of SCT.

Results: A total of 157 surveys were completed between April 2019 and February 2020. Mean age was 22 years (SD of 7.6 years). 35% and 58% of respondents identified as Black and Latino respectively **Figure 1**. Overall, 72% of respondents stated they knew their SCT status and 28% reported they did not know their status. 46.5% and 62.4% of respondents had never heard of SCD and SCT respectively, while 66.9% had never been spoken to about SCD by a healthcare provider. Respondents older than 21 years were more likely to know their SCT status compared to those who were 21 years or younger, OR = 2.74 (95% CI: 1.24–6.09). There was no statistical difference in SCT status knowledge between respondents who reported being born in the United States or outside the United States **Figure 2**.

Conclusion: A significant fraction (28%) of respondents were not aware of their SCT status among a population with significant sickle cell prevalence (approximately 10% of U.S SCD patients are in New York State). These findings support the need for more education and awareness and the need for improved mechanisms to be put in place in order to communicate SCT status (universally available through the newborn screen) to adolescents early enough to be able to consider family planning practices using the knowledge of their SCT status. We believe that this awareness of one's SCT status would lead to a reduction in the incidence of SCD and improve the health of the population.

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KEYWORDS:

SCD: Sickle Cell Disease; SCT:
Sickle Cell Trait; CI: Confidence
interval; SD: Standard
deviation; OR: Odds ratio

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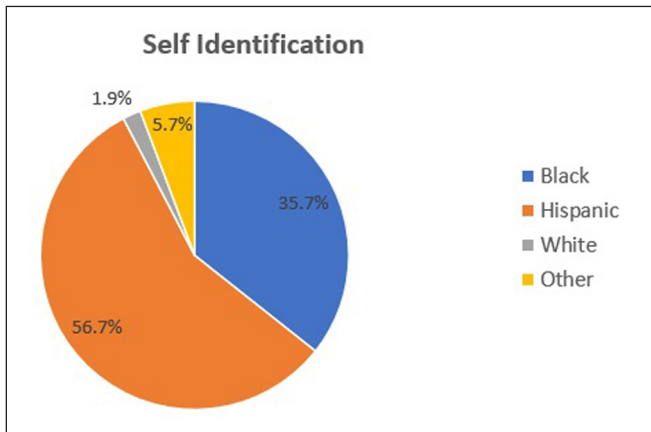


Figure 1 Self identification chart with majority reporting being hispanic or black.

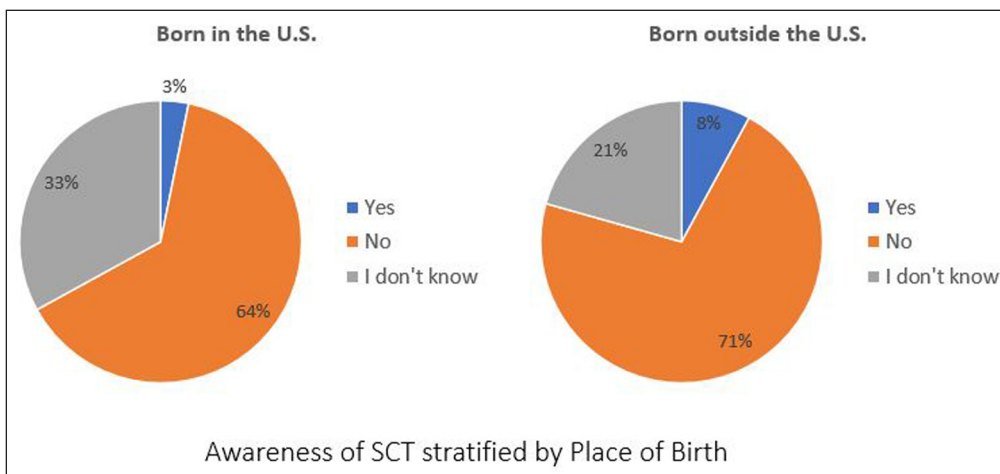


Figure 2 Awareness of SCT status stratified by place of birth, showing more awareness among respondents born outside the U.S.

COMPETING INTERESTS

The authors have no competing interests to declare.

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