Inadequate Community Knowledge about Sickle Cell Disease among African-American Women

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Background: Federal legislation was passed in 1972 initiating genetic screening and community education about sickle cell disease (SCD). Few assessments have examined the impact of these programs. The aim of this study is to assess existing knowledge about SCD among African-American women in St. Louis, MO.

Methods: We conducted a cross-sectional telephone survey of African-American women, 18–30 years of age. Participants were recruited through random-digit dialing in six ZIP codes with greater than 75% African-American residents. The survey contained questions exploring four content domains about SCD: general knowledge, genetics, management and educational resources.

Results: A total of 264 women were contacted; 30% were unable to complete the survey and participate further because they were unaware of SCD. One-hundred-sixty-two women met eligibility criteria, agreed to be surveyed and were included in the study. Ninety-one percent of the participants believed that SCD was a hereditary blood disorder, but only 9.3% understood the inheritance pattern. Eleven percent of the women were unaware of their sickle cell trait status. Most women recognized pain (94%), infections (80%) and strokes (40%) as complications of SCD.

Conclusion: New strategies are needed to enhance awareness of SCD among African-American women of childbearing age.

Key words: sickle cell anemia ■ public health education ■ survey ■ knowledge, attitudes and practice ■ women's health ■ reproductive health

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INTRODUCTION

Sickle cell disease (SCD) is the most common genetically inherited disease affecting African Americans. Approximately one in 12 African Americans will have sickle cell trait, and approximately one in 400 African-American newborns will be diagnosed with SCD annually.[1] Prior to the 1970s, few programs were dedicated to providing the public with information on SCD. Early community-based surveys conducted in large urban areas demonstrated limited awareness of SCD among African Americans in these communities.[2,3]

In 1972, the National SCD Control Act set the foundation for universal screening of newborns for SCD.[4] In addition to focusing on the reduction of SCD-related morbidity and mortality, the national legislation promoted community awareness of SCD by providing education and genetic counseling programs to patients and families with sickle cell trait and SCD. In the St. Louis metropolitan area, the St. Louis City Public Health Department has been responsible for hemoglobinopathy screening and SCD education for over 30 years. The Missouri Sickle Cell Anemia Program was established in 1973, and the Yeatman Union Sarah Health Center, St. Louis, was one of the first funded agencies in the state of Missouri (St. Louis City Department of Health) designed to educate African Americans about SCD. Currently, funding for the program is maintained by the Missouri State Department of Health and appropriated to the St. Louis City Department of Health. The program is responsible for providing genetic counseling to parents of newborns with sickle cell trait or other hemoglobinopathies and educating the community about SCD.

The PRECEDE/PROCEED model for behavior and health promotion was used to structure a framework for improving the African-American community's awareness about SCD.[5] As part of a descriptive study, we conducted a community survey to evaluate existing knowledge of SCD. The aim of this study was to assess existing knowledge about SCD in African-American women in St. Louis.

METHODS

Data Collection

The Institutional Review Board at Washington University School of Medicine approved this study. An independent marketing research corporation, Fleming Communications, conducted a cross-sectional telephone survey of African-American women in the St. Louis metropolitan area from July 31, 2001 to August 17, 2001. Individuals were iden-

Table 1. Assessment Survey Questions

Question: Have you ever heard of sickle cell disease (SCD)?

Question: Which of the following are true of SCD:
A. SCD is a blood disease.
B. There are many different types of SCD.
SCD can be identified by a blood test.
Blood transfusions are an important way of treating SCD

Question: Who gets SCD?
A. Only African Americans
B. Mostly African Americans
C. All races are equally as likely
D. Don't Know/ refused

Question: Thinking about how common SCD is, among African Americans would you say it affects...
A. 1 in every 100 blacks
B. 1 in every 500 blacks
C. 1 in every 1000 blacks
D. 1 in every 10,000 or more blacks
E. Don't know/refused

Question: How do you get SCD?
A. You are born with it (It's hereditary)
B. You get it from a blood transfusion
C. You can get it some other way
D. Don't know/refused

Question: Does SCD sometimes skip generations in families?

Question: Do you know if there are different types of traits that can lead to SCD?

Question: Do you know, if you, personally, have sickle cell trait?
A. Yes I have it
B. No I don't have it
C. Don't know/refused

Question: Have you ever heard of C-trait?
If yes: Question: Do you know, if you, personally, have C-trait?
A. Yes I have it
B. No I don't have it
C. Don't know/refused

Question: Have you ever heard of b-thalassemia trait? If yes: Question: Do you know, if you, personally, have Beta-thalassemia trait?
A. Yes I have it
B. No I don't have it
C. Don't know/refused

Question: Would you say that children with SCD are more likely to develop the following conditions due to the disease:
A. pain requiring hospitalization
B. life threatening infections
C. kidney failure
D. stroke

Question: To what extent do you agree or disagree that "SCD can impact a child's school performance?"
A. Strongly Agree
B. Agree
C. Neither agree nor disagree
D. Disagree
E. Strongly Disagree
F. Don't know/ Refused

Question: Is there currently a cure for SCD?

Question: What would you say is the best way to increase awareness about SCD in the black community?
A. Mail out written information or pamphlet
B. Hold informational meetings in community
C. Publicize on TV
D. Publicize on radio
E. Distribute a video or CD about SCD
F. Other
G. Don't know/refused

tified through random-digit dialing of a population of 5,500 names determined from ZIP codes documented to have more than 75% of the population as African-American according to the 2000 Missouri Census data. Five ZIP codes were identified in St. Louis City (63107, 63112, 63113, 63115, 63120) and one ZIP code was identified in St. Louis County (63136). All participants required a telephone at their home address to participate in the study. Demographic information was collected, and participation was limited to African-American women 18–30 years of age who had graduated high school. Study participants were initially asked if they were aware of SCD. Those who were unaware of SCD were not asked further questions and excluded. Interviews were only carried out with individuals who identified themselves as African-American. This age group was selected based on data from the Missouri State Health Department indicating that the majority of births occurring among African-American women take place within this age group.[6] African-American women who met the above inclusion criteria were asked to continue answering a series of questions. Survey questions consisted of closed-ended questions across four content domains: general knowledge about SCD, genetics of SCD, complications of SCD and management of SCD (Table 1).

RESULTS

Enrollment and Demographics

Two-hundred-sixty-four women were contacted through the telephone survey. Ten women declined the interview, and 13 women began the interview but did not finish. Thirty percent of the women were not able to participate further in the study because they had not heard of SCD. A total of 162 African-American women met all eligibility criteria, completed the survey and were included in the analysis. All individuals graduated from high school, and 69% had some college education. The median annual income for ZIP codes surveyed was $21,000.[10]

Basic Knowledge of SCD

The women who completed the interview had a good understanding of basic information about SCD but were unaware of how common SCD is among African Americans. Approximately 90% of those interviewed (n=162) were aware that SCD is a blood disorder that could be detected with a blood test. Fifty-six percent of the women correctly asserted that SCD affects mainly African Americans, but 30% believed that SCD affects all races equally. Additionally, only 27.2% (44/162) knew the approximate incidence of the disease among African Americans.

Table 2. Awareness of Sickle Cell Disease Complications among 162 African-American Women 18 and 30 Years of Age

	Yes (%) (Agree Strongly Agree or Agree)	No (%) (Disagree Strongly or Disagree)	Don't Know (%) (Neither Agree nor Disagree)
Pain requiring hospitalization	94	1	4
Life threatening infections	80	8	11
Kidney failure	64	14	23
Strokes	40	25	35
Poor school performance	84	8	9

Table 3. Comparison of Response to Study Question, "Have You Ever Heard of Sickle Cell Disease (SCD)?" in Three Surveys of African-American Communities

Article	Study Location	Number of Respondents	Educational Status of Respondents	Demographic Surveyed	Percent of Respondents Who Didn't Know about SCD
Lane & Scott[2]	Richmond, VA	686	At least high-school graduate	African-American adults	70
Young et al.[3]	Cleveland, OH	76	Unknown	Head of household	38
Current Study	St. Louis, MO	162	At least high-school graduate	African-American women	30

Genetics of SCD

Many women understood that SCD is an inherited disorder but had limited knowledge about the inheritance pattern of SCD. Ninety-one percent of women agreed that an individual is born with SCD; however, 6% believed one could get it from a blood transfusion or another manner. Less than 10% of the women surveyed understood the inheritance pattern of SCD; most believed that SCD skips generations. The majority of the women surveyed (52%) were unaware of the different types of SCD. Only 36% (58/162) and 12% (20/162) were aware of C-trait and ß-thalassemia trait, respectively (Figure 1). Within this group, even fewer women were aware of their personal trait status (Figure 2). Most women (90%) believed that they knew their sickle cell trait status, 27% knew their C-trait status, and only 10% knew their ß-thalassemia trait status.

Complications and Treatment Associated with SCD

The women surveyed recognized pain as the most common complication of SCD. They were also aware of other serious complications associated with SCD (Table 2). Ninety-four percent of the women believed that pain requiring hospitalization was a complication of SCD. Eighty percent believed that children with SCD may have life-threatening infections. Sixty-four percent believed that children with SCD may develop kidney failure, and 40% believed that strokes can occur in this population. Eighty-four percent agreed or strongly agreed that SCD may impact school performance.

Treatment strategies for SCD were poorly understood among those interviewed. Only 44% understood that blood transfusions were an important therapy for treating SCD. Eighty-six percent believed that no cure is available for SCD, failing to recognize that human-leukocyte-antigen (HLA)-matched sibling stem cell transplant can offer a cure for SCD.

Educational Resources for SCD

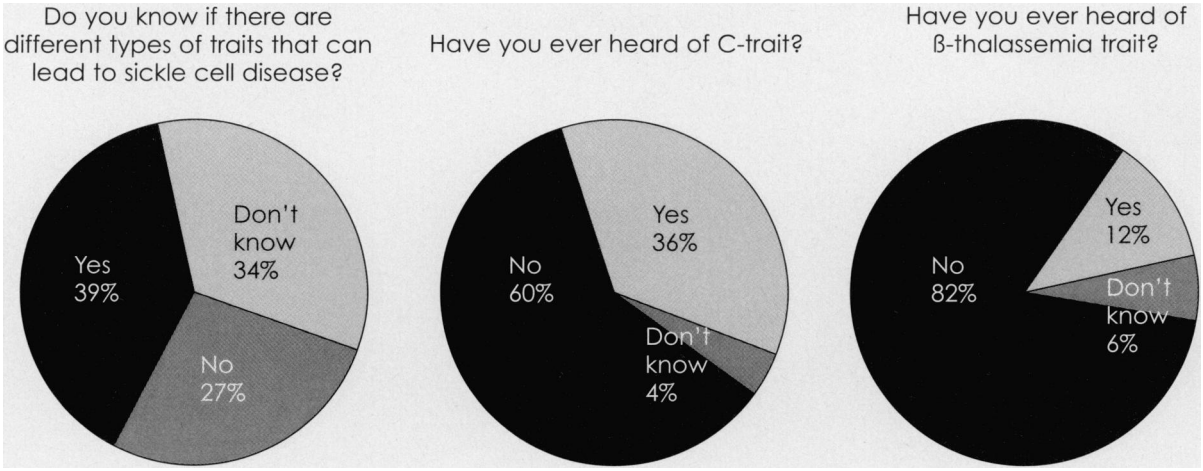
The preferred approaches for increasing awareness about SCD by participants surveyed included providing information through different media. Approximately one-third of the participants identified pamphlets (36%) and educational meetings (36%) followed by television (31%) and radio (28%) announcements as the most effective ways to educate African Americans about SCD.

DISCUSSION

The results of our study indicate that 30% of the African-American women of childbearing age in the study are unaware of SCD. Of those who completed the survey, most women understood that SCD was a hereditary blood disorder but did not understand the inheritance pattern and believed that SCD skipped generations. The results of this survey and others indicate that African-American women have not been equipped with adequate information about the incidence and inheritance patterns of SCD essential to making informed decisions about having a child with SCD.[3,4]

Our data is comparable to other studies assessing community knowledge. In November 1968, 1,457 African Americans (over 15 years of age) in Richmond, VA were interviewed. Approximately 70% (441/1457) were not aware of SCD, including 53% (361/686) of those who had completed high school

Figure 1. Knowledge of Phenotypes Associated with Sickle Cell Disease in 162 African-American Women between 18 and 30 Years of Age



and 34% (118/342) of those with some college education.[3] In a similar survey conducted in 1971, 76 African-American heads of household (mean age=46) in Cleveland, OH were surveyed, and 38% (29/76) of those surveyed were unaware of SCD.[4] The types of questions asked in the current study were comparable to the two previous studies (Table 3). Despite 30 years in time, the results of these community studies were remarkably similar to our findings.

In addition to assessing the knowledge about SCD in the African-American community, we also wanted to know if the women were aware of the most serious complications associated with SCD. Surprisingly, most women were aware that SCD can result in pain requiring hospitalization, life-threatening infections, increased risk of kidney failure, strokes and poor school performance. Collectively, these results suggest that major morbidities associated with SCD are at least acknowledged by African-American women. Unfortunately, most women did not know that HLA-matched sibling stem cell transplant is a cure for SCD.

The results of this survey suggest that the preferred methods to learn about SCD were pamphlets, educational meetings and radio and TV announcements. This information provides a framework for developing and evaluating strategies to educate African-American women about the disease. Additionally, these strategies may be employed to improve understanding and raise awareness about the importance of blood and cord blood donations as therapeutic options for SCD.

As with all cross-sectional, random-digit dialing surveys, our study has inherent limitations. The study population is limited to households with telephones, which excludes approximately 5.4% of households in the study area.[7] Additionally, our results only reflect responses from women ages 18–30 years of age. However, determining the awareness in this segment of the population is important because the majority of births among African-American women in St. Louis occur within this age group.[6] Lastly, to our knowledge, no standard set of questions have been used to assess knowledge about SCD. Future studies would benefit from the inclusion of similar questions to determine the reliability of such questions in assessing knowledge about SCD.

Our results provide strong evidence that African-American women are poorly informed about the genetics associated with having a child with SCD. New strategies are needed to effectively educate African-American women about SCD and enhance their ability to make informed decisions about having a child with SCD. Further study is needed to determine the effectiveness of these strategies in educating African-American women of childbearing age about SCD.

ACKNOWLEDGEMENT

Funding was provided by NIDDK: 1RO1 DK62619-01 and Doris Duke Foundation: 19990573.

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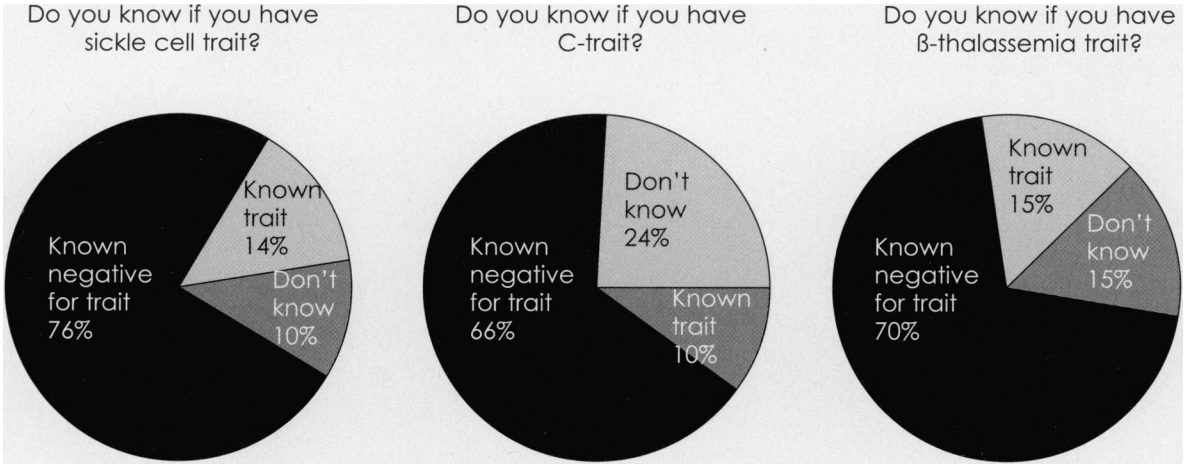
Figure 2. Personal Knowledge of Hemoglobin Trait Status in African-American Women Aware of Different Types of Sickle Cell Disease



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