Using Qualitative and Quantitative Strategies to Evaluate Knowledge and Perceptions about Sickle Cell Disease and Sickle Cell Trait

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Objectives: To evaluate knowledge, perceptions and the effectiveness of different sources of information about sickle cell trait (SCT) and sickle cell disease (SCD); to determine individual knowledge of SCT status.

Methods: 28 individuals participated in three focus groups (healthcare providers, people affected by SCD or SCT, and community members). Surveyors interviewed 282 respondents within their neighborhoods.

Results: Common themes across the focus groups included the limited general awareness of SCD and SCT, the emphasis on the benign nature of SCT rather than on future implications, and the need for public health education campaigns about SCD and SCT involving media strategies. The majority of community survey respondents (n=243, 86.2%) had correct general knowledge about the genetic basis and severity of SCD, but only 16% (n=45) knew their own trait status. When respondents had received information about SCD from friends and acquaintances, they were three times more likely to know their SCT status, compared with respondents who had not received information from a personal source ($p<0.01$).

Conclusions: Despite a screening history in the 1970s fraught with controversy, sickle cell disease management and detection can be a model for the empowerment of communities in making informed decisions about theirs and their families' futures, given the burgeoning of genetic information.

Key words: sickle cell disease ■ African Americans ■ health promotion

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INTRODUCTION

Sickle cell disease (SCD) is an inherited blood disorder that affects 80,000 individuals—primarily African Americans—in the United States, but it can also be found in Mediterranean, East Indian, Caribbean and Latino populations. Symptoms of SCD usually appear after early infancy and typically persist throughout the lifespan.[1] Clinical manifestations of SCD include pain, increased risk of infection, chronic anemia, cerebrovascular events and progressive organ damage.[2] While individuals with SCD are at risk for early mortality, the disease course is variable.[3] The one cure—bone marrow transplantation—is available to a limited number of patients who have an human leukocyte antigen (HLA)-matched sibling.[4]

Highly accurate and cost-effective technologies are available for screening for SCD and sickle cell traits (SCT). There is limited well-designed research on the association of SCT status with health consequences, but there is evidence of increased risk of hyposthenuria and hematuria,[5,6] sickling under extreme conditions (e.g., excessive exertion and high altitudes[7-9]), eye abnormalities[10] and an increase in the expression of microvascular diabetic complications in the presence of SCT.[11]

It is particularly important for individuals with SCT to understand the implications for reproduction. Children born to two parents with SCT have a 25% chance of having SCD and a 50% chance of having SCT. Newborn screening allows for the early diagnosis of newborns with SCD with attendant close medical follow-up. Families of infants identified with SCT are offered testing and counseling about the risk for having a child in the future who has SCD in many U.S. states.[12] However, systematic evaluations of newborn screening programs that support disclosure of infants' SCT status on parents have not been undertaken.[13]

There is also limited information about public knowledge, perceptions and attitudes about SCD and SCT,[14] and individuals in high-risk groups often

do not know their own trait status.[15-17] In a study of 147 African-American patients aged 18–50 years seen in an emergency department, 73% knew SCD was a genetic disorder, but only 31% knew their own trait status.[15] In another study, 23% of a sample of patients with SCD incorrectly believed SCT can change into SCD.[17]

Effective public health education[18] for SCT and SCD would address misconceptions, result in accurate understanding of the risks of having a child with SCD and influence personal decisions about family planning. In the 1970s, SCT screening was associated with coercive reproductive politics as well as insurance and employment discrimination.[19] Sickle cell education, counseling and genetic screening became fraught with controversy and, as a result, the African-American community has regarded SCT screening and follow-up with distrust, for what was deemed "a black disease."[20,21] With this historical backdrop, it remains unclear what strategies support informed reproductive decision-making about SCD in communities at greatest risk.

In 2001, in northern California, <18% of families who were notified that their infants were SCT carriers followed up with free counseling to learn more about SCT and about the risk for SCD in future pregnancies. This lack of follow-up, not uncommon throughout the United States, prompted the creation of community-based grants by the Maternal and Child Health Bureau for the Sickle Cell Disease and Newborn Screening Program, with the goal of improving SCT follow-up, including notification, extended family testing, counseling and education.

As recipients of a community-based award, we utilized qualitative and quantitative strategies to delineate the general level of awareness and understanding about SCD and SCT, and specific individual knowledge about SCT status in the community. Very few population-based community surveys addressing knowledge and perceptions about SCD and SCT have been conducted since the early 1970s.[14,22]

METHODS

The study took place in the East Bay region of northern California, a metropolitan area that has one of the most economically and ethnically diverse populations in the country. This population is distributed across several regional urban and suburban centers. The Northern California Comprehensive Sickle Cell Center (NCCSCC) is located in Oakland, CA and serves all of northern California. Newborn screening follow-up for the region is a collaboration between the NCCSCC and the State of California Genetic Disease Branch. The institutional review board of the sponsoring community hospital approved the study.

Focus Groups

We first conducted a series of focus group assessments with the goals of: 1) identifying barriers to SCT follow-up; 2) gathering perceptions of the general awareness of SCD; 3) generating potential solutions to the problem of low rate of trait follow-up. Three separate focus group assessments were conducted at the sponsoring community hospital. Ten healthcare providers (four physicians, three nurses, three ancillary staff—eight were females, 40% were African-American and 60% were Caucasian) who worked directly with patients with SCD and who had first-hand knowledge of issues related to SCD and SCT participated in the first group.

The second group was recruited to represent the perspectives of people directly affected with SCD or SCT and consisted of five patients with SCD (age 13–55 years—four women and one adolescent male, all African American) and three family members of patients (three women with SCT—two African-American and one Latino). The third group, representing the target community, consisted of four men and six women (all African-American) from the neighboring areas of the hospital.

The focus group assessments were conducted using commonly accepted strategies[23,24] by an African-American woman at the master's level in a counseling program who had training in ethnographic methods. Participants were recruited through a newsletter and flyers posted at such community locales as stores and restaurants, and were reimbursed for their time and travel. After obtaining informed consent from each participant, the "ground rules" were explained (e.g., confidentiality, allowing each member to respond to every question and the permissibility of cross-discussion). The questions used in the focus group assessments had been previously piloted to evaluate ease of understanding and to determine if they were worded to elicit the material of interest. Responses were tape-recorded and transcribed for analysis.

Community Surveys

Neighborhood surveys were conducted with the goals of: 1) determining the extent of community members' exposure to different sources of information about SCD and SCT in the past year; 2) evaluating community knowledge about SCD and SCT; 3) determining if individuals actually knew their own trait status and 4) evaluating the effectiveness of different sources of information about SCD and SCT in improving knowledge. The survey was administered in an interview format and took 5–10 minutes to complete. The surveys had been previously piloted to evaluate ease of understanding and to determine if they were worded to elicit the material of interest. The

target age of those surveyed was 18–44 years (reproductive age). Three-hundred-sixteen individuals from three counties with a mean representation of 36.4% African Americans were formally interviewed.

The team of 10 African-American and Latino female surveyors was made up of residents in the communities being surveyed. They were educated about SCD and trait, and were instructed and supervised on how to conduct the surveys. Regular meetings were held during the data collection period of four weeks to discuss any concerns or problems and to ensure that reliability was maintained. Survey sites included homes, stores, schools, libraries and community centers in the selected census tracts, and all passers-by in public places, as feasible, were solicited. Survey respondents were screened to determine if they had lived in the area for ≥3 months and if they were in the targeted age group. Thirty-four surveys were discarded because of missing responses to key questions, leaving 282 surveys for the final analysis. Surveys that were discarded did not differ demographically from those retained.

The text from the transcripts of the focus groups was categorized using content analysis,[25] and recurring themes across all three groups were identified. Data from the community surveys were entered into an SPSS version 12.0 database for Windows®.[26]

RESULTS

Focus Groups

Illustrative responses of the common themes across the healthcare provider, sickle cell and general community groups are listed in Table 1.

Focus group participants across all three groups agreed that there is limited visibility of and knowledge about SCD and SCT in the general population. All three groups endorsed the importance of using media to improve awareness. In addition, the three groups noted that healthcare providers bear responsibility for the community's lack of awareness about SCD and providers needed to improve in educating their individual patients about SCD and SCT.

Themes not common to the three groups included the stigma attached to the disease that was noted by people affected by SCD and SCT and the general community but not by healthcare providers (e.g., "people...with sickle cell are embarrassed; being unhealthy is a taboo." "Children ... face stigmatization, fear and ostracism." "... they don't want to be ridiculed, so they keep quiet."). The sickle cell and general community groups expressed their opinions that "compassion," "love and nurturing" and "honesty (from doctors)" are solutions to the problem of lack of support for people with SCD. On the other hand, the healthcare providers emphasized a need for more outreach and for education in the community, from grade school through college. Healthcare providers and the sickle cell group, but not the general community group, noted that more basic and clinical research is needed about sickle cell disorders. Finally, only group members directly affected by SCD commented on the severity of the disease.

Community Surveys

Sixty-six percent (n=186) of respondents were

Table 1. Recurring themes across provider, sickle cell and community focus groups

Question Posed to Group Participants Illustrative Responses
What Are Reasons for Poor Follow-Up with Trait Counseling?
Parents don't understand trait, do not think it affects them
The concept of the trait is too abstract to grasp
Lack of education in the community, most have no idea
Primary healthcare providers focus on benign nature of trait, not on future implications
What Will Improve Follow-Up with Trait Notification?
Need more education—media—to catch the public's attention
Someone that has an influence in society being the spokesperson, such as Oprah, sports stars
What Can Improve Support for People with Sickle Cell Disease and Their Families?
Need to increase visibility, a lot of people don't know about it
Incentives for community to get involved
Outreach—health fairs at community colleges, high schools and in lower grades
Educating healthcare providers
Other Thoughts and Ideas about Improving Awareness of Sickle Cell Disease and Trait?
It should be taught in school from the beginning—grade school, middle school and high school

women, with a mean age of 32.7 (SD=9.52) years; 64.9% (n=183) were single, 23.8% (n=67) were married.

The most frequent sources of information about SCD and SCT were friends/acquaintances, magazine articles, health department brochures, community agencies and television (Table 2). Using McNemar's test to determine if there were different sources of information for SCD and SCT, it was found that participants received significantly more information about SCD from more than one source.

Participants were split into two groups by median age—45% (n=127) were <33 years; 53.5% (n=155) were >33 years. Demographically, the groups differed only on marital status, with the younger group more likely to be single ($t(230)=5.92$, $p<0.01$). Compared with the younger age group, participants aged >33 years were more likely to have received information about SCD from radio ($t(56)=-2.02$, $p<0.05$) and were more likely to have received information about SCD ($t(250)=-2.64$, $p<0.01$) and SCT ($t(239)=-2.58$, $p<0.05$) from a community organization.

Two-hundred-forty-three (86.2%) of the respondents correctly indicated that SCD causes serious health problems. Ninety-one percent stated that SCD is found mostly in African-American populations. Over 68% (n=192) responded correctly to knowledge questions about SCD (Table 3).

The majority of respondents (86.2%, n=243) correctly knew that SCD is inherited from both parents. Seventeen percent (n=48) incorrectly believed that SCD can be acquired through a blood transfusion, and 8.9% (n=25) incorrectly believed that it is contagious.

Respondents were asked to generate their own definition of SCD, and responses were classified as completely correct, partially correct and incorrect. A completely correct definition included some reference to "sickling of the red blood cells" *plus* reference to the hereditary nature of the disease. Using this scheme, 13.1% (n=37) of respondents provided a completely correct definition of SCD and 16.7% (n=47) provided a partially correct definition. Thirty percent stated that SCD is "a blood disease" without further explanation. Forty percent (n=113) of respondents gave "don't know" or an incorrect answer, with some definitions consistent with iron deficiency anemia.

Seventy percent (n=197) of respondents endorsed that SCT causes health problems. Thirty-one percent incorrectly believed that SCT can turn into SCD. The majority of respondents knew the genetic significance of trait, with 81.6% (n=230) correctly responding "if you have SCT, you can have a child with SCD," and 78% (n = 220) correctly responding that "your child with SCT might have a child with SCD in the future."

Only 15.9% (n=45) of the respondents knew their own trait status. Respondents could indicate that they learned about their trait status from multiple sources, and 53.3% (n=150) reported that they learned of their status from their family; 35.5% (n=100) were tested in the community; and 75.5% (n=213) were tested at a hospital or in a clinic.

Correct responses to questions regarding SCT and SCD were summed and cross-referenced with the participants' source of information. Exposure to *any* information source about SCD resulted in a mean of 6.7 out of a possible eight correct responses about SCD, versus a mean of 6.3, with no exposure ($t(280)=2.26$, $p<0.05$). Receiving SCD information from a community organization was the most effective source associated with correct responses, compared with other sources ($\chi^2(7)=19.89$, $p<0.01$). No significant effect was found based on respondents'

Table 2. Differences in responses to survey question: "In the past year, have you received information about sickle cell disease or sickle cell trait (carrier state)? (Please check [✔] all that apply.)"

Information Received about:	Sickle Cell Disease		Sickle Cell Trait	
Source	**N**	**%**	**N**	**%**
Television	54	19.1	36	12.8**
Radio	36	12.8	24	8.5
Magazine articles	62	22.0	43	15.0**
Newspaper articles	36	12.8	26	9.2
Billboard, store, bus signs	50	17.7	20	7.1*
Brochures				
Health department	60	21.3	44	15.6**
School	32	11.3	27	9.6
Church	15	5.3	6	2.1*
Community agencies	55	19.5	37	13.1**
Friends/acquaintances	83	29.4	60	21.3**

McNemar's test * p<0.05; ** p<0.01

exposure to one or multiple sources of information.

Exposure to any information source about SCT resulted in a mean of 2.3 out of four possible correct responses, versus a mean of 2.2 with no exposure—this difference had no statistical significance. No one source of information was associated with more correct responses. When correct responses about SCT were compared based on exposure to one or multiple sources, no significant effect was found.

Gaining information about SCD from a personal source such as a friend or acquaintance was the only source that was significantly related to knowledge of one's own trait status. Twenty-six percent (n=73) of those who knew their trait status had gained information from a personal source, contrasted with 13.3% (n=37), who had *not* received information from a personal source ($\chi^2(4)=12.98$, $p<0.05$).

A logistic regression analysis was performed to learn more about the relations between variables and knowledge of trait status (Table 4).

For the 39 respondents who did not know that SCD is genetically transmitted, there was a perfect prediction to their also not knowing their SCT status. Therefore, knowledge that SCD is genetic could not be included in the regression model. Gender and age were not significant predictors of knowledge of trait status. Knowing that SCD is serious was associated with higher odds of knowing one's SCT status; however, this had no statistical significance. Getting information from friends/acquaintances had a strong and significant effect on knowledge of trait status, with respondents who had received information from this source being almost three times more likely to know their trait status versus those who did not receive information from a personal source.

Men were more likely to believe that SCD can be acquired through a blood transfusion ($t(144)=2.36$, $p<0.05$), and women were twice as likely as men to know that SCT carriers are at risk for having a child with SCD ($t(240)=3.01$, $p<0.01$). Women were more likely to have been tested through a hospital, clinic or physician's office ($t(258)=-2.83$, $p<0.01$). Participants ages ≤33 were more likely to believe that SCD can be acquired through a blood transfusion ($t(238)=2.32$, $p<0.05$) and were less likely to know that SCD is genetically transmitted ($t(222)=2.71$ $p<0.01$) compared with participants aged >33.

DISCUSSION

There is limited information available about improving SCT follow-up, including notification, extended family testing, counseling and education in at risk communities. A baseline of community perceptions, knowledge and attitudes about SCD and SCT needs to be established to provide a foundation for effective interventions. Our findings are similar to those of a recent telephone survey of African-American women in the midwest[14] and remarkably similar to findings from previous surveys done more than 25 years ago.[22] These persistent gaps in knowledge about sickle cell in the community suggest that effective strategies are needed to educate those most at risk, and other health promotion and disease prevention campaigns may be germane for SCD and SCT.[27-29]

The importance of targeting informal networks has been emphasized in other health education campaigns for African Americans,[27,30,31] consistent with our finding that the only source of information about SCD that was related to knowledge of one's trait status was friends and acquaintances. Focus group members directly affected by SCD and SCT underscored the need for counseling about SCT that is perceived as trustworthy. Peer educators and advance practice nurses who have experience with high-risk, underserved clients may be effective in delivering information that is easily understood by individuals within the community, and their understanding of the culture, religious beliefs and ethical values of the community may enhance their credibility in an historically distrustful community.[27]

The convergence of survey and focus group results highlighted the importance of media campaigns as an effective means of increasing awareness of SCD and SCT. This is consistent with data from meta-analyses of persuasion principles applied to other public health education that emphasize multiple strategies and messages to "get the word out."[32] Innovative venues for disseminating information about SCT might include daycares and small businesses.[26] Counseling and testing must also be easily accessible, particularly for

Table 3. Correct responses to survey question: "True or false: people with sickle dell disease ... (Please check [✓])"

	Number of Correct Responses	
Survey Question	**N**	**%**
Can have more infections	192	68.1
Can be physically active	227	80.5
Can live long and healthy lives with good medical care	237	84.0
Can outgrow it	223	79.1

men, who in our study had accessed traditional public health policies and programs less often than women. Couples at risk may need to be instructed in the use of "behavioral scripts" that insure adequate discussions of safer sex, prevention of unwanted pregnancy and the risk of a pregnancy that might result in a child with a serious chronic illness.[32] Such specific communication instruction could also address the knowledge gap between men and women. There has not been any follow-up to Rowley's[16] finding that pregnant women with SCT in one study expressed that they were afraid to talk with their partners about their trait status. Addressing gender influences remains a critical point in designing effective health promotion strategies.

Healthcare providers must be sensitive to the anxiety that can arise with the identification of SCT, including the misconception that SCT evolves into SCD. After newborn screening, primary healthcare providers should follow up with families to clarify the future risk for the family and for the child identified with trait, for having a child with SCD, despite the benign nature of SCT. Our findings suggest that providers underestimate the extent to which fear of stigmatization may impact follow-up for treatment and even testing for SCT, and the importance of communicating a caring attitude along with their expertise. At the same time, with the burgeoning amount of genetic information available to both providers and consumers, it is not realistic for patients to rely solely on their healthcare providers for this information. Providers can keep up-to-date references that meet standards for health literacy readily available in their offices. These references might include easily navigated Internet sites and multimedia sources where the content has been endorsed for accuracy by local or national sickle cell organizations.

Focus group participants recommended that education about SCD and SCT should occur from elementary school through college, and the knowledge differences between older and younger participants in the present survey accentuate this need. School health programs that focus on improving the health of school personnel, students and the community[28] provide one model for the provision of health education across the lifespan.

Limitations

Some of the survey items were structured so that the participants' exact knowledge or awareness of SCD and SCT remains unclear, as exemplified by the frequent definition of sickle cell disease as "a blood disease." There may have been other barriers to participants' learning about their own trait status that were not identified, such as anxiety about the screening process itself or the potential test results. Perceived or real lack of access to counseling and testing might also have been a barrier. The present study only looked at exposure to sources of information about SCD and SCT without any evaluation of how memorable or instructive the information really was. However, this effort is an important step in giving a voice to communities most at risk and in determining future strategies to improve understanding of the interrelations between knowledge, awareness and behaviors related to SCD and SCT. Ultimately, policy and practice[33,34] in the provision of information meant to empower these communities in making informed decisions about their own and their families' futures can be influenced.

The way forward. African Americans fare worse than all other groups in the United States on all health indices, as defined by Healthy People 2010 goals. Health intervention models and theories that emphasize community empowerment and utilize traditional and nontraditional networks are vital for the dissemination of information about SCD and other diseases that predominantly affect African Americans. Future surveys should be conducted in other regions to determine if these findings extend beyond a northern Californian, predominantly African-American, urban sample and should be structured to allow participants to provide more comprehensive responses about specific barriers to learning about their trait status. The effectiveness of intervening media campaigns to increase awareness, knowledge and behaviors should be assessed. Efforts are underway to improve access to resources about genetic testing for individual healthcare providers and for state-administered screening programs.[35] These will help ensure that these providers and programs are truly a source of accurate and current information about SCD and SCT.

Table 4. Logistic regression predicting knowledge of trait status

Variable	z	SE	Odds Ratio
Gender	1.69	0.02	1.03
Age	0.78	0.53	1.36
Knowledge SCD is serious health	1.84	6.97	6.72
Learned about SCD from friends/acquaintances	2.85	0.99	2.77**

**p<0.01

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