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Feasibility of a Community-Based Sickle Cell Trait Testing and Counseling Program

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ABSTRACT
Background: Sickle cell trait (SCT) screening is required at birth in the United States; however, adults rarely know their SCT status prior to having children.
Purpose: Assess feasibility of a community-based SCT education and testing intervention.
Methods: Participants were recruited from eight community sites to complete an educational program and offered a hemoglobin analysis. A genetic counselor met individually with participants to discuss lab results.
Results: Between July 14, 2010 and May 31, 2012, 637 participants completed the educational program. Five hundred seventy (89.5%) provided a blood sample, and 61 (10.9%) had SCT or other hemoglobinopathies. The genetic counselor met with 321 (56.3%) participants.
Conclusions: Community-based SCT testing shows initial feasibility and may increase the number of individuals who know their trait status.

Keywords: Sickle Cell Disease, Sickle Cell Trait, Community-Based Research**,** Health Education, African Americans

INTRODUCTION

Sickle cell disease (SCD) is an autosomal recessive disease and contributes to racial health disparities in the United States (US). Approximately 100,000 individuals in the US have SCD, which causes multisystem morbidities, including risk of early death (Gustafson, Gettig, Watt-Morse, & Krishnamurti, 2007; Hassell, 2010; Panepinto, Magid, Rewers, & Lane, 2000). Comprising a heterogeneous group of inherited blood hemoglobinopathies; the most common types of SCD include Hb SS (sickle cell anemia), Hb SC, and Hb Sβ thalassemia (Hb Sβ thal). SCD occurs in about 1 in 500 African Americans, 1 in 36,000 Hispanics and 1 in 80,000 Whites (Panepinto et al., 2000; Rogers, Powars, Kinney, Williams, & Schroeder, 1989). For those of

African descent, SCD is the most commonly inherited single gene disorder (Gustafson et al., 2007; Lonergan, Cline, & Abbondanzo, 2001; Wethers, 2000).

From 1970 to 2010, the life expectancy for individuals with SCD increased from 20 to 50 years of age (Quinn, Rogers, McCavit, & Buchanan, 2010). This increase in life expectancy may be a result of advances in newborn screening, prophylactic penicillin, and effective vaccinations for common childhood diseases (Quinn et al., 2010). Although life expectancy has increased for individuals with SCD, it is still 25-30 years lower than the average life expectancy for African Americans in the overall US population (Platt et al., 1994).

Heterozygous carriers of one SCD gene have sickle cell trait (SCT) and are found throughout the US. While the highest prevalence of traits that can lead to SCD is found among individuals of African descent, SCT is also found in those of Asian, Indian, Latin American, Mediterranean, and Middle Eastern descent (Gustafson et al., 2007; Lonergan et al., 2001; Wethers, 2000). SCT has a protective mechanism against malaria; therefore, people from tropical regions are more likely to carry the trait (Allison, 1954). Hemoglobin S trait (Hb AS), C trait (Hb AC), and β thalassemia trait (Hb Aβ thal) affect approximately 1 in 12, 1 in 50, and 1 in 100 African Americans respectively (Ashley-Koch, Yang, & Olney, 2000). Approximately 1 in 183 Hispanics have SCT (Ashley-Koch et al., 2000). Given the diverse populations at risk for SCT, an increased awareness of the consequences of SCT is warranted.

Prenatal testing for sickle cell trait

Voluntary testing and counseling programs have targeted individuals at-risk for carrying one of the genetic traits for SCD, beginning with the 1972 National Sickle Cell Anemia Control Act (Olney, 1999). However, these programs have had limited success informing individuals at-risk for SCT of their status and providing inheritance education before having children. For example, in a survey of 264 African American women in 2005, 30% had never heard of SCD (Boyd, Watkins, Price, Fleming, & DeBaun, 2005). Of the 70% who had heard of SCD, 90% believed that it was an inherited blood disease, but only 9% correctly understood the inheritance pattern (Boyd et al., 2005). Genetic testing to identify couples at-risk of having children with hemoglobinopathies is recommended, and individuals who are at higher risk should be provided counseling about reproduction and prenatal diagnosis (American College of Obstetricians and Gynecologists, 2007).

Currently, in the St. Louis, MO metropolitan area, no coordinated agency exists to provide systematic trait testing or genetic counseling for individuals at-risk for SCT. Surveys and site visits conducted by the former Sickle Cell Screening and Counseling Services Program of the City of St. Louis Department of Health between 2001 and 2002 evaluated sickle cell services provided to prenatal patients at 17 clinics in St. Louis City and County. Results from this survey showed: (1) a majority of prenatal clinics offered SCT testing to African American women but not other women, (2) male partner screening was infrequent, but clinics did offer referrals for free testing, (3) most clinics offered brief counseling by a nurse without formal SCT counseling training, (4) and few clinics notified patients of negative results (Althouse-Hill, personal communication, October 15, 2013; Sickle Cell Screening and Counseling Services Program of the City of St. Louis Department of Health, Unpublished Data, 2013). Pregnant women who test positive for SCT do not know if they are at-risk for having a baby with SCD unless they know the trait status of the father. But, as the Department of Health study revealed, most health clinics in St. Louis were not testing partners. Furthermore, the free trait testing and counseling offered through the City of St. Louis Department of Health was discontinued in 2005 (Althouse-Hill,

personal communication, October 15, 2013; Sickle Cell Screening and Counseling Services Program of the City of St. Louis Department of Health, Unpublished Data, 2013).

Newborn screening for SCD and SCT

Missouri's newborn screening program for sickle cell disease began in 1989. The program identifies newborns with SCD, connecting parents and caregivers to early education about SCD management. Parents of these infants also receive information regarding SCD inheritance and their chances of having another child with SCD. For infants born with SCT, it is recommended that both parents be tested for SCT and counseled to discuss their potential risk for having a child with SCD. Approximately 1,500 individuals with SCT were identified through this program during its implementation from 1989 to 2005 (Althouse-Hill, personal communication, October 15, 2013; Sickle Cell Screening and Counseling Services Program of the City of St. Louis Department of Health, Unpublished Data, 2013). While the parental screening and SCT testing program was discontinued in 2005, state newborn screening continues. In 2012, 38 infants in Missouri with SCD were identified (Althouse-Hill, personal communication, October 15, 2013; Sickle Cell Screening and Counseling Services Program of the City of St. Louis Department of Health, Unpublished Data, 2013).

Despite nearly universal screening for SCD and SCT in newborns in the US and Missouri, adults often do not know their SCT status before having children (Acharya, Lang, & Ross, 2009). Infants identified at birth with SCT are rarely aware of their trait status as adults (Holtzman, 1993; Wright, Zeldin, Wrenn, & Miller, 1994). Emphasis on reproductive life planning for individuals with SCD is recommended in the guidelines for SCD published by the National Heart Lung and Blood Institute (National Institutes of Health, 2002; National Institutes of Health, 2014). These guidelines state that children tested for SCT as infants "may not recall or understand the implications by the time they reach childbearing age" (p. 19) (National Institutes of Health, 2002). Young adults with SCT are unlikely to make informed decisions regarding trait status if their parents do not understand the importance of trait education (National Institutes of Health, 2002). This may account for the unchanged prevalence of SCT in the population, despite mandatory newborn screening.

In 2007, Washington University School of Medicine was awarded a genetic services grant from Health Resources and Services Administration (HRSA) to investigate the feasibility of offering grant-funded SCT testing and sickle cell inheritance education at no cost to the participant. Using a community-based approach in populations at high risk for SCD or SCT, our goal was to increase the number of individuals who know their SCT status.

Hypothesis

We sought to determine if this community-based program was feasible by testing two primary hypotheses: (1) The majority (>50%) of African American adults who are unaware of their SCT status will request testing after completing a sickle cell inheritance education program and (2) The majority (>50%) of those who provide a blood sample for SCT testing will attend a genetic counseling session at a neighborhood health center.

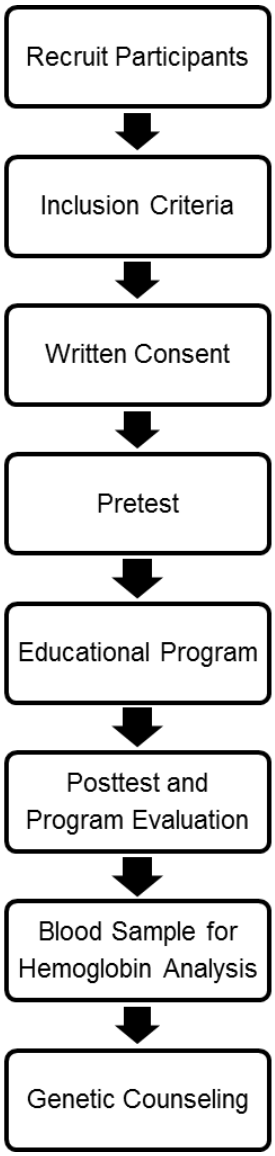
A secondary aim was to improve understanding of SCT and how it is inherited by offering educational programming aimed at individuals in the African American community. We hypothesized that participants who complete the sickle cell inheritance education program will show an increased knowledge of trait inheritance according to pre-post assessments.

METHODS

Study Design and Procedures

We performed a mixed-methods cross-sectional study assessing the feasibility of implementing a community-based trait testing and educational program. Feasibility was defined as the majority (>50%) of participants request testing after the sickle cell inheritance education program and the majority (>50%) of those who are tested for SCT will complete genetic counseling. We identified >50% as a demand and implementation feasibility measure to help assess whether this intervention should be recommended for efficacy testing in the future (Bowen et al., 2009). A secondary aim was to improve understanding of sickle cell inheritance through an educational program using a pre- and posttest assessment. The Institutional Review Board of the Human Research Protections Office at Washington University School of Medicine approved this study (IRB #201104185).

Figure 1. Study design and procedures.



Population and Setting

Participants were initially recruited from three locations of an urban St. Louis Federally Qualified Health Center (FQHC). These FQHCs serve as healthcare safety nets in our urban metropolitan area. Previously, our sickle cell disease research team mapped the area within the metropolitan region with highest SCD patient population from our medical center. These three FQHC locations had the highest cluster of patient density, and the majority of their patients are African American. In order to reach more of the target population, four additional community programs (church health fairs, community monthly health screening at a public library, a nursing conference, and a minority scientist showcase) were included in the education and testing program. Lastly, a university-initiated community program to increase inclusion of underrepresented populations in research also served as a research site.

Recruitment

Participants were recruited from the FQHC or community event (Figure 1). Recruitment fliers and posters were used at community locations. In addition, the university-initiated community program recruited participants who met our inclusion criteria. We also placed a newspaper advertisement in the St. Louis American, a weekly paper serving the St. Louis African American Community, for the FQHC program.

Inclusion criteria

Initially, inclusion criteria were defined as: (1) Ages 15 to 49 years (the range generally used by the World Health Organization for reproductive age); (2) Attendance at a sickle cell inheritance education program; (3) Parent or guardian consent for those under 18 years of age. Participants were excluded if they were not English speakers.

Upon implementation, the research team received feedback from participants to adjust the age range to include more individuals. Several older adults outside the age inclusion criteria wanted to participate so they could inform family members if they may be at-risk for carrying SCT. Upon consulting our advisory board of medical professionals and lay community members, we adapted the program to include ages 14-60 years. All participants completed written consent. Minor participants were required to have parental consent.

Data Collection

Measures

The number of participants, testing location, results and genetic counseling frequencies were recorded to determine feasibility of the program. In addition, participants completed a 10 question true/false pretest to assess their baseline knowledge of SCD and SCT. The posttest was the same as the pretest and completed after the educational program. Participants were also asked to complete a nine question program evaluation to help assess demand and implementation feasibility (Bowen et al., 2009). These materials were developed by the same multidisciplinary team that created the educational program.

Sickle cell trait testing. After the posttest and individual program evaluation, participants were asked if they would like to be tested for SCT. Those requesting trait testing had their blood drawn for hemoglobin analysis. Full hemoglobin analysis was chosen because it is the standard care for genetic testing and more comprehensive than Sickledex testing, which identifies only Hb AS and fails to identify Hb AC, Hb Aβ thal and other traits. Laboratory results from trait testing were sent to a genetic counselor at the FQHC and to the principal investigator. After conferring with the principal investigator regarding the test results, the genetic counselor contacted the participants and scheduled a counseling session, approximately 14 days after participants were

tested. The counseling sessions were held at the FQHC and the university-initiated program to recruit community participants. Participants were given one gift card ($10) after the educational program and a second gift card ($15) after counseling.

Educational program

As part of the formative work for this study, a multidisciplinary team developed educational materials to promote SCT testing among African American families, who were identified as the priority population. Using the recommended program development stages of formative research, message development, pretesting and message refinement, the multidisciplinary team created their messaging strategy (U.S. Department of Health and Human Services, 2002). We included the priority population of community members in developing and evaluating these educational materials. Community members were recruited at an urban, inner city FQHC.

This 15-minute educational program explained traits, genetic inheritance, and general information about SCT and SCD. Staff from a FQHC and a local African American Fraternal Organization led this community-based effort. The educational program was developed to ensure that community members with basic training could become sickle cell educators enabling them to lead the educational program. Educators were trained and demonstrated command of the content to increase fidelity during implementation. After training, staff from the FQHC, members from the Fraternal Organization, and Washington University research staff became sickle cell inheritance educators.

The educational program could be completed with one sickle cell inheritance educator and one or more participants

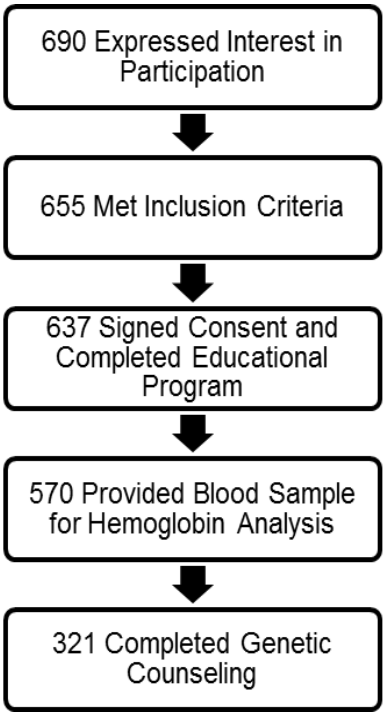
Data analysis

The number of participants, testing location, results and genetic counseling frequencies were recorded. Pretest, posttest, and individual program evaluation were also captured and analyzed. Frequencies and descriptive statistics were generated. Pearson X^2 was used to assess relationships between participant demographic characteristics and genetic counseling since these categories had greater than five participants in each group. Paired t-tests and Fisher's Exact were used as indicated to analyze pre- and posttest data. Fisher's Exact was chosen because there were questions with less than five participants in the category. SPSS statistical package was used for all analyses.

RESULTS

From 2010 to 2012, 690 individuals expressed interest from eight testing sites (Figure 2). Six hundred fifty-five (655) met the inclusion criteria. Six hundred thirty-seven (637) participants consented and 570 provided a blood sample for testing.

Figure 2. Participants in a Community-Based Sickle Cell Trait Education Program



The majority of participants were female (62.7%), and the average age was 40 years (40.0 ± 12.6; range: 14-60). About 86% of participants were African American Two-thirds of participants who reported marital status were single. Approximately 20% of participants who reported education level had not completed high school. Over half of participants (56.3%) who reported on employment status were unemployed (Table 1).

Table 1. Participant Demographics in a Community-Based Sickle Trait Education Program

Variable	n (%)
Total Participants	637 (100)
Gender (n=526)	
Female	330 (62.7)
Not Reported	111
Age (yrs)	
Mean ± SD, Range	40.0 ± 12.6 (14-60)
Race/Ethnicity (n=270)	
African American	232 (85.9)
African American and one or more than one other race/ethnicity	14 (5.2)
White/Caucasian	10 (3.7)
Other	14 (5.2)
Not Reported	367
Marital Status (n=604)	
Single	402 (66.5)
Married	95 (15.7)
Divorced/Separated	94 (15.6)
Other	13 (2.1)
Not Reported	33
Education Level (n = 506)	
<12th Grade	102 (20.2)
High School Graduate/ GED	190 (37.5)
Some College/College Degree	214 (42.3)
Not Reported	131
Employment (n = 522)	
Full-Time	151 (28.9)
Part-Time	77 (14.8)
Not employed	294 (56.3)
Not Reported	115

Participants tested for SCT

Five hundred seventy participants (89.5%) were tested for SCT. Ten participants provided a blood sample but the sample was unable to be used for hemoglobin analysis per laboratory report. Most participants (89.1%) had normal hemoglobin (Hb AA) with the remaining participants having some type of hemoglobinopathies (Table 2). Sixty-seven participants (10.5%) elected to not have their blood drawn. Of the participants who reported ethnicity/race as African American or African American and another ethnicity/race (n=246), 26 (10.6%) had SCT.

Table 2. Hemoglobin Frequencies

Type	Frequency n (%)
Hb AA	499 (89.1)
Hb S Trait—AS	42 (7.5)
Hb C Trait—AC	11 (2.0)
Hb A/ β thalassemia Trait -- Aβ thal	4 (0.7)
Sickle Cell Disease (SCD- Hb SC)	1 (0.2)
Other Hemoglobinopathies	3 (0.5)
Blood Drawn; Unable to Complete Hemoglobin Analysis	*10*
Blood Not Drawn	*67*
Total Participants	637

The Health Protection and Education Services (a monthly health screening service), in a close St. Louis suburb, had the highest percentage of people electing to be tested (96.9%). Of the participants who did not have their blood drawn, the most commonly cited reason was time constraint. A limited number of participants were unable to have their blood drawn due to time limitations of the phlebotomist. If this occurred, they were provided with alternative locations and times for testing.

Genetic counseling

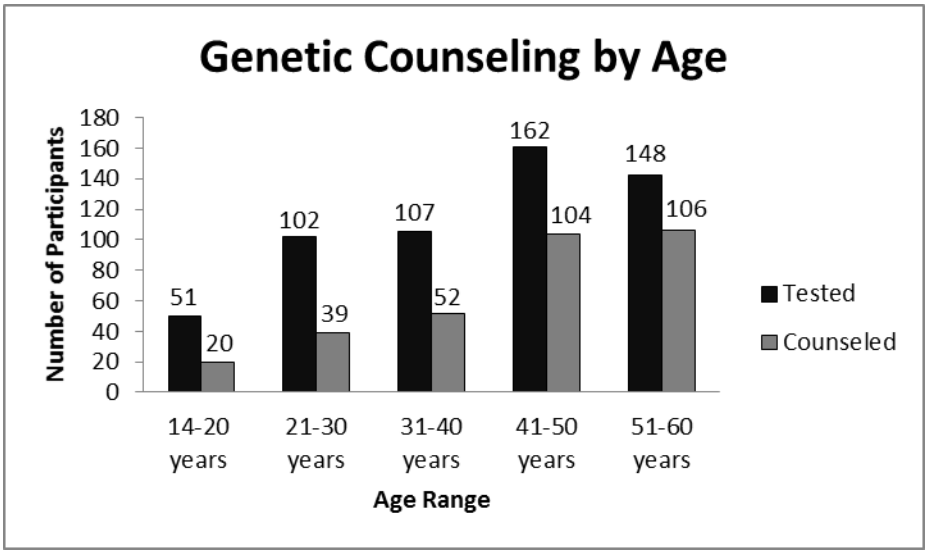
Of the 570 participants who were tested, 321 (56.3%) met with the genetic counselor to receive their results. The 10 individuals with insufficient blood samples were eligible for genetic counseling and offered repeat testing. These participants were included in this analysis since the participants did elect to provide a sample and attempted to complete the genetic counseling. Participants tested at a FQHC or university-initiated community program were significantly more likely to complete genetic counseling (Pearson X^2= (2, n=570)= 67.0 p<.001). Other community health events attended by the sickle cell testing team had the lowest rate of genetic counseling (34.4%). Of the 560 participants who were able to obtain trait results, participants who tested positive for a hemoglobinopathy (Hb AS, Hb AC, Aβ thal, Hb SC, other hemoglobinopathy) were not significantly more likely to complete genetic counseling compared to individuals who tested with normal (Hb AA) hemoglobin (Pearson X^2= (1, n=560)= 2.0 p=.16).

Table 3. Frequencies of Genetic Counseling by Location

Location	Trait Tested	Genetic Counseling n (%)
Federally Qualified Health Center (3 Locations)	167	121 (72.5)
University-Initiated Community Program	191	127 (66.5)
Other Community Events	212	73 (34.4)
TOTALS	**570**	**321 (56.3)**

Only six of the 51 participants aged 14-20 years attended sessions at the university-initiated community program. A majority of participants 14-20 years were recruited from FQHCs and community events. Age was a significant predictor of completing genetic counseling (Pearson $X^2(4, n=570)= 40.4$, $p <.001$). Generally as age increased, the rate of genetic counseling increased (Figure 3).

Figure 3. Genetic Counseling by Age



Educational program pretest and posttest

The pretest and posttest assessment used prior to and immediately after the educational program included 10 identical true/false statements. Questions were a short prompt and participants were asked to circle true or false (e.g. Diseases can be passed down from parents to children. True False). Four hundred twenty-seven (427) completed most questions on the pretest and posttest. Overall, there was a significant difference between the pretest (M=7.30, SD=1.34)

and posttest (M=7.80, SD=1.23) scores (t(426)=-6.91, p=<.001).

We used Fisher's exact test for individual question analysis. All questions demonstrated significant difference between the pretest and posttest answers (Table 4).

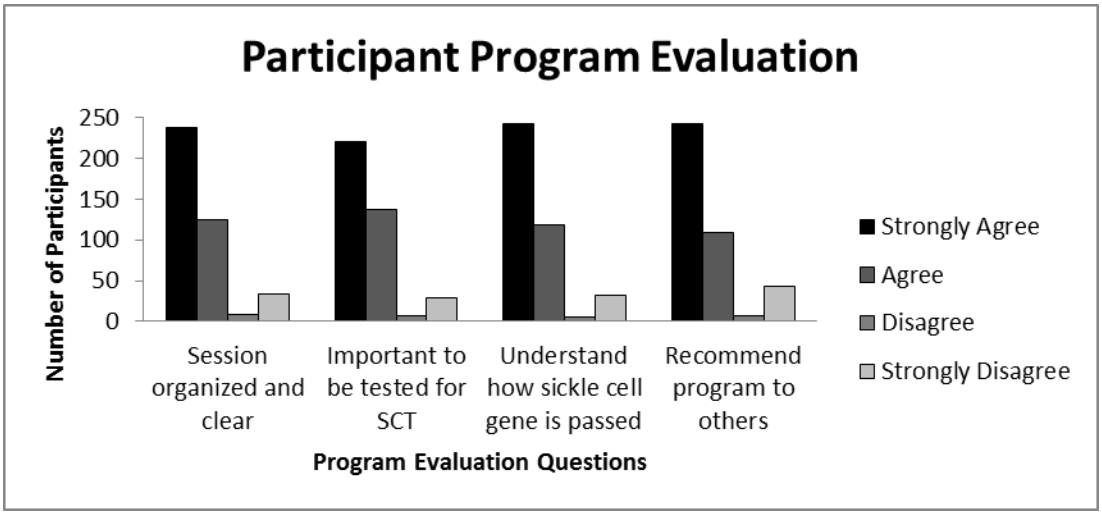
Table 4. Question level analysis for pretest and posttest results

Question	Fisher's Exact	P-value
1. Traits like hair color and height are inherited from our parents.	(1, n=426)	p <.001
2. Traits are passed from parents to children on genes.	(1, n=427)	p =.001
3. A baby's sex is determined by genes from the mother.	(1, n=423)	p <.001
4. Diseases can be passed down from parents to children.	(1, n=427)	p =.007
5. Sickle cell disease and sickle cell trait are the same.	(1, n=426)	p <.001
6. You can have sickle cell trait and not even know it.	(1, n=426)	p =.006
7. People with sickle cell trait can become ill or die if they exercise too hard.	(1, n=423)	p <.001
8. Both parents must have sickle cell disease for their baby to have the disease.	(1, n=425)	p =.002
9. If one parent has sickle cell disease, all children will at least have trait.	(1, n=426)	p <.001
10. If both parents have sickle cell trait, all children will have trait.	(1, n=425)	p =.001

Participant program evaluation

Evaluations consisted of 4 questions (similar to Likert-Scale), 1 yes/no question, and 4 open-ended questions. Participant evaluations demonstrated support of this community-based education and testing program. Over 85% of participants agreed or strongly agreed that the program was clear, it is important to be tested for SCD, they understand how SCD is passed and that they would recommend this program to others. Some examples of the comments on the evaluation included, "All of the information was helpful and now I know more than I did" and "I found that having the trait doesn't mean that you have the disease."

Figure 4. Frequencies of Responses in Participant Evaluation



DISCUSSION

The results of this current study suggest that community-based SCT testing can be successfully implemented and may increase knowledge of trait status. By working with community organizations within the priority population, the research team engaged participants at high risk for SCT. Almost 90% (89.5%) of participants were tested for SCT and 60% (56.3%) of participants completed the entire testing and genetic counseling. This suggests that the priority population is interested in knowing their SCT status, meeting demand and implementation feasibility measures (Bowen et al., 2009). With feasibility measures met, we recommend future efficacy testing.

For the current investigation, the rate of SCT was consistent with previously published findings. Prevalence of sickle trait (Hb AS, Hb AC, Hb Aβ thal) in the tested population was 10.2% compared to approximately 11.3% (Ashley-Koch et al., 2000; Whitten & Whitten-Shurney, 2001) in the US as previously reported.

Educational Program Pretest and Posttest

Even with a significant change in the pretest and posttest results, the improvement was smaller than anticipated. While the change was significant (pretest: M=7.30, SD=1.34 and posttest: M=7.80, SD=1.23; t(426)=-6.91, p=<.001) there may be limited meaning in an average score increase of 0.50. A 0.50 increase in may not reflect a true increase in knowledge.

The pretest and posttest assessments need further evaluation. Although the Flesch-Kinkaid reading level was less than grade 6, the subject matter may have been have been hard to understand for the population. Almost 60% of participants reported less than a 12th grade education or reported a high school diploma or GED. Research team members noted pretests with higher scores than posttests and evaluations with comments indicating approval of the program but with the participant selecting the contradicting "strongly disagree" as a response to the evaluation questions about the efficacy of the program. (Figure 4). In previous studies assessing knowledge of SCD, less than 10% correctly understood the inheritance pattern and transmission of SCD (Boyd et al., 2005; Treadwell, McClough, & Vichinsky, 2006). Working with health literacy experts in the planning phase of the next stage of work will be imperative to both educational efforts and assessment.

In the current investigation, prior to the educational program, 269 (63.1%) participants (n=426) incorrectly (false) answered the question: "If one parent has sickle cell disease, all children will at least have trait." In addition, almost half (47.1%) of participants incorrectly believed that if both parents have SCT, all children would have trait. This shows that there is a misunderstanding of SCD and SCT for the participants prior to the educational program. With the exception of question eight ("Both parents must have sickle cell disease for their baby to have the disease") participants scored higher on the posttest compared to the pretest, indicating increased knowledge of sickle cell inheritance, but further assessment is needed. A validated knowledge measure is needed. Demand and implementation feasibility demonstrate the need for this program and assessment development.

Recruitment

We recruited participants aged 14-60 years. Our goal was to recruit individuals, both male and female, during child bearing years. In recruiting participants ages 14-60 years, we captured individuals prior to, during, and possibly after their child bearing years. By testing adults who may already have children, we could discuss SCT and family inheritance with the goal that this may compel parents to discuss SCT testing with their children who may be planning a family. Moreover, families attended these community events together resulting in parents and children, siblings and intimate partners often electing to be tested together.

Limitations

There were several limitations with the community-based design. All participation was voluntary and was presented as a health education opportunity. Not all participants completed all forms, so data are missing. However, the results of trait distribution were consistent with the literature so the population is likely representative of African American communities.

We provided a $10 gift card for their initial participation and a $15 gift card for completing the genetic counseling, to acknowledge participant time. Over half (56.3%) of the participants who reported their work status reported being unemployed. As a result, participants may have been more interested in the gift card compensation rather than knowledge of sickle cell. However, most participants showed a genuine interest during the educational sessions and went out of their way to return for genetic counseling.

In addition, only six of the 51 participants aged 14-20 years attended sessions at the university-initiated community program. The university-initiated program worked with other research studies that may not have included youth participants. Recruiting adolescents and young adults from organizations that have existing relationships or provide services to this age group may be a more successful recruitment strategy.

Notable findings

Participants were significantly more likely to complete genetic counseling if it was offered at the location where they were tested. Those who were tested at a FQHC or university-initiated community program completed genetic counseling at significantly higher rates compared to those who were tested out in the community. One possible explanation for this is that participants knew where to complete counseling since they had been to the location. Our five additional community sites were often annual or monthly events that did not lend to providing genetic counseling at the same location. Additionally, the FQHC and university-initiated community program offer other health services and therefore participants could schedule their genetic counseling at the same time as another scheduled appointment.

While young adults are most likely to become parents (the average age for African American women at first childbirth is 20.9 years, and for men it is 23.3) (Abma, Martinez,

Mosher, & Dawson, 2004; Chandra, Martinez, Mosher, Abma, & Jones, 2005; Martinez, Daniels, & Chandra, 2012), participants less than 30 years were the least likely to complete genetic counseling. In general, as age increased, more participants completed genetic counseling. This could indicate that older adults are more concerned about their status for their families and children. For youth 14-20 years, they may require a different approach for genetic counseling, perhaps a peer to peer or a more mobile approach rather than attending counseling face-to-face (Porter et al., 2014). Providing a smart phone application or website with trait results and genetic counseling may meet the needs of this younger population. Moreover, providing SCT education in schools may also be an effective way to reach this population.

Using a community-based model to address testing and counseling

The impetus for the proposed program evolved from the priorities established by an advocacy group made up of members from a FQHC, an African American Fraternal Organization and a university-based SCD treatment and education team. All agreed that knowledge of SCD and trait status should be a priority for at-risk adolescents and adults in the St. Louis area. This program added an important component to the range of services currently provided by the FQHC and Fraternal Organization. In addition, it filled a need currently unmet in the St. Louis community, and, most importantly, empowered people at-risk of having a child with SCD to make informed reproductive health decisions through community outreach efforts.

In the absence of trait screening programs, too many parents discover they have SCT and/or learn about the implications of their trait status when their newborn is diagnosed with SCD. Potential parents who know their trait status and the sickle cell inheritance pattern before they make reproductive decisions are empowered to make use of the full range of options available to them. Given the absence of any formal system in the St. Louis area to adequately inform individuals about their risk of having a child with SCD, a new strategy must be undertaken to educate and offer testing to individuals at-risk for carrying SCT. This strategy could include web-based education and also a platform to link adults with their state newborn screening results.

The community-based approach was essential to the success of this program. Through community networks, trait testing occurred at five additional priority locations to maximize our engagement with the priority population. Team members would not have been aware of these critical locations without our community partners. Moreover, involving the community stakeholders with material development for the educational program aided the health literacy and cultural relevance of the materials. By incorporating an advisory board, comprised of community members, patients, parents, and medical professionals with an interest in SCD, helped to assess the relevance of the program. With their feedback and community connections, we were able to continue growing and developing the program for the priority population.

We shared the results of this investigation throughout the community. Community members could request the sickle cell inheritance education program at schools, churches, corporations and other community centers. During these educational events, we included the most up-to-date results from our trait testing.

CONCLUSION

The most important finding from this study was that almost 90% of African Americans in the community who learned of our program were interested in learning more about sickle cell and willing to be tested. With almost 60% of participants completing testing and genetic counseling, our community-based strategy meets feasibility measures. Overall, participants who

completed the educational program scored higher on the posttest indicating short-term efficacy in knowledge gain of sickle cell. Posttest gains were limited, and therefore considerations for literacy and health literacy need to be explored further. Despite nearly universal testing for SCD and SCT in newborns in the US and Missouri, a program is needed to ensure that adults know their SCT status. A community-based educational and trait testing program demonstrates feasibility and could be used to address this public health challenge.

REFERENCES

Abma, J. C., Martinez, G. M., Mosher, W. D., & Dawson, B. S. (2004). Teenagers in the United States: sexual activity, contraceptive use, and childbearing, 2002. *Vital and Health Statistics. Series 23, Data from the National Survey of Family Growth*(24), 1.

Acharya, K., Lang, C. W., & Ross, L. F. (2009). A pilot study to explore knowledge, attitudes, and beliefs about sickle cell trait and disease. *Journal of the National Medical Association, 101*(11), 1163-1172.

Allison, A. C. (1954). Protection afforded by sickle-cell trait against subtertian malarial infection. *British Medical Journal, 1*(4857), 290.

Althouse-Hill, N. (October 15, 2013). [Personal Communication].

Ashley-Koch, A., Yang, Q., & Olney, R. S. (2000). Sickle hemoglobin (Hb S) allele and sickle cell disease: a HuGE review. *American Journal of Epidemiology, 151*(9), 839-845.

Bowen, D. J., Kreuter, M., Spring, B., Cofta-Woerpel, L., Linnan, L., Weiner, D., . . . Fabrizio, C. (2009). How we design feasibility studies. *American Journal of Preventive Medicine, 36*(5), 452-457.

Boyd, J., Watkins, A., Price, C., Fleming, F., & DeBaun, M. (2005). Inadequate community knowledge about sickle cell disease among African-American women. *Journal of the National Medical Association, 97*(1), 62-67.

Chandra, A., Martinez, G. M., Mosher, W. D., Abma, J. C., & Jones, J. (2005). Fertility, family planning, and reproductive health of US women: data from the 2002 National Survey of Family Growth. *Vital and health statistics. Series 23, Data from the National Survey of Family Growth*(25), 1.

Evidence-Based Management of Sickle Cell Disease: Expert Panel Report. (2014): National Heart, Lung and Blood Institute, US Department of Health and Human Services, National Institutes of Health.

Green, L. W., & Glasgow, R. E. (2006). Evaluating the relevance, generalization, and applicability of research - Issues in external validation and translation methodology. *Evaluation & the Health Professions, 29*(1), 126-153. doi: 10.1177/0163278705284445

Gustafson, S. L., Gettig, E. A., Watt-Morse, M., & Krishnamurti, L. (2007). Health beliefs among African-American women regarding genetic testing and counseling for sickle cell disease. *Genetics in Medicine, 9*(5), 303-310.

Hassell, K. L. (2010). Population estimates of sickle cell disease in the US. *American Journal of Preventive Medicine, 38*(4), S512-S521. doi: 10.1016/j.amepre.2009.12.022

Holtzman, N. A. (1993). Primary care physicians as providers of frontline genetic services. *Fetal Diagnosis and Therapy, 8*(Suppl. 1), 213-219.

Lonergan, G., Cline, D., & Abbondanzo, S. (2001). Sickle cell anemia. *Radiographics: a Review Publication of the Radiological Society of North America, Inc, 21*(4), 971.

Martinez, G., Daniels, K., & Chandra, A. (2012). Fertility of men and women aged 15-44 years in the United States: National Survey of Family Growth, 2006-2010. *National Health Statistics Reports*(51), 1.

National Institutes of Health. The Management of Sickle Cell Disease. (2002). In: National Heart Lung and Blood Institute, Division of Blood Diseases and Resources, ed. 4th ed: NIH Publication No. 02-2117.

American College of Obstetricians and Gynecologists. ACOG Practice Bulletin No. 78: hemoglobinopathies in pregnancy. *Obstetrics and Gynecology.* 2007;109(1):229-237.

Olney, R. S. (1999). Preventing morbidity and mortality from sickle cell disease - A public health perspective. *American Journal of Preventive Medicine, 16*(2), 116-121. doi: 10.1016/s0749-3797(98)00140-8.

Panepinto, J. A., Magid, D., Rewers, M. J., & Lane, P. A. (2000). Universal versus targeted screening of infants for sickle cell disease: a cost-effectiveness analysis. *The Journal of Pediatrics, 136*(2), 201-208.

Platt, O. S., Brambilla, D. J., Rosse, W. F., Milner, P. F., Castro, O., Steinberg, M. H., & Klug, P. P. (1994). Mortality in sickle cell disease--life expectancy and risk factors for early death. *New England Journal of Medicine, 330*(23), 1639-1644.

Porter, J. S., Matthews, C. S., Carroll, Y. M., Anderson, S. M., Smeltzer, M. P., & Hankins, J. S. (2014). Genetic Education and Sickle Cell Disease: Feasibility and Efficacy of a Program Tailored to Adolescents. *Journal of Pediatric Hematology/Oncology, 36*(7), 572-577.

Quinn, C. T., Rogers, Z. R., McCavit, T. L., & Buchanan, G. R. (2010). Improved survival of children and adolescents with sickle cell disease. *Blood, 115*(17), 3447-3452. doi: 10.1182/blood-2009-07-233700

Rogers, Z. R., Powars, D. R., Kinney, T. R., Williams, W. D., & Schroeder, W. A. (1989). Nonblack patients with sickle cell disease have African βs gene cluster haplotypes. *Journal of the American Medical Association, 261*(20), 2991-2994.

Treadwell, M. J., McClough, L., & Vichinsky, E. (2006). Using qualitative and quantitative strategies to evaluate knowledge and perceptions about sickle cell disease and sickle cell trait. *Journal of the National Medical Association, 98*(5), 704-710.

U.S. Department of Health and Human Services. (2002). *Making Health Communication Programs Work*. Bethesda, MD: National Cancer Institute.

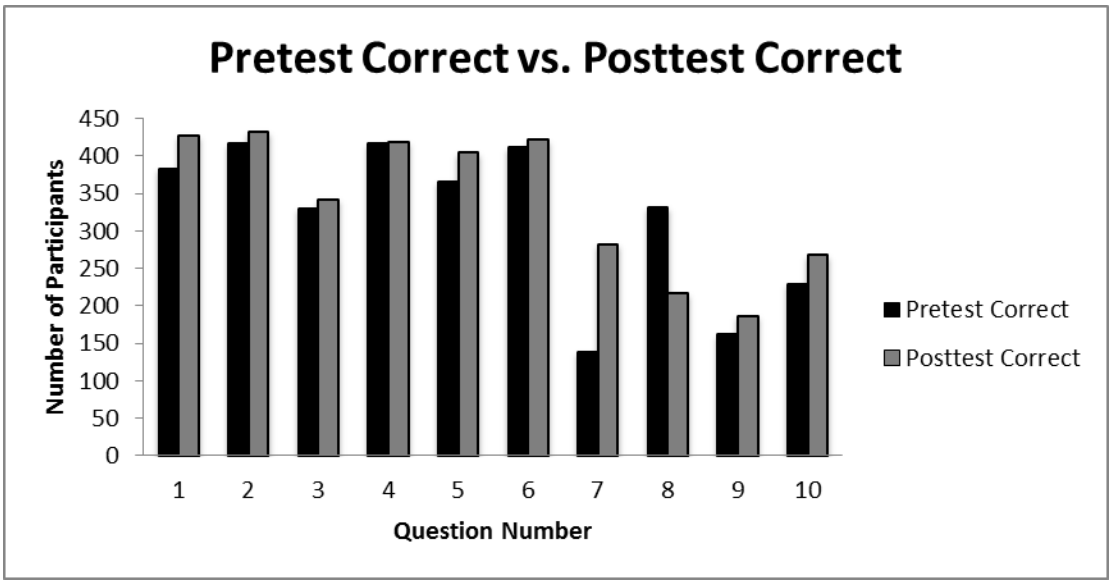
Sickle Cell Screening and Counseling Services Program of the City of St. Louis Department of Health. 2013. [Unpublished Data].

Wethers, D. (2000). Sickle cell disease in childhood: Part I. Laboratory diagnosis, pathophysiology and health maintenance. *American Family Physician, 62*(5), 1013-1020, 1027-1018.

Whitten, C. F., & Whitten-Shurney, W. (2001). Sickle cell. *Clinics in Perinatology, 28*(2), 435. doi: 10.1016/s0095-5108(05)70095-6

Wright, S. W., Zeldin, M. H., Wrenn, K., & Miller, O. (1994). Screening for sickle-cell trait in the emergency department. *Journal of General Internal Medicine, 9*(8), 421-424.

Appendix 1. Pretest Correct vs. Posttest Correct.



Pretest and Posttest results.

Appendix 2. Pretest and Posttest Measure.

Sickle Cell Genetics Quiz

1. Traits like hair color and height are inherited from our parents. True False
2. Traits are passed from parents to children on genes. True False
3. A baby's sex is determined by genes from the mother. True False
4. Diseases can be passed down from parents to children. True False
5. Sickle cell disease and sickle cell trait are the same. True False
6. You can have sickle cell trait and not even know it. True False
7. People with sickle cell trait can become ill or die if they exercise too hard. True False
8. Both parents must have sickle cell disease for their baby to have the disease. True False
9. If one parent has sickle cell disease, all children will at least have trait. True False
10. If both parents have sickle cell trait, all children will have trait. True False

Appendix 3. Participant Education Program Evaluation.

Sickle Cell Trait Testing Education Program Evaluation

We want to know if the information about how sickle cell disease is inherited has been helpful to you. Please circle the answer that best describes how you feel about the educational program.

1. The class session was organized and presented clearly.

1 Strongly Disagree 2 Disagree 3 Don't know 4 Agree 5 Strongly Agree

2. The brochure helped me understand why it is important to be tested for sickle cell trait.

1 Strongly Disagree 2 Disagree 3 Don't know 4 Agree 5 Strongly Agree

3. The presentation helped me understand how the sickle cell gene is passed from parent to child.

1 Strongly Disagree 2 Disagree 3 Don't know 4 Agree 5 Strongly Agree

4. I would recommend these classes to others.

1 Strongly Disagree 2 Disagree 3 Don't know 4 Agree 5 Strongly Agree

5. Did you decide to have your blood tested today? **Yes No**

If not, why?

6. How did you hear about this class? Sign at health center, flyer, newspaper ad, health care provider, radio,

Other _____

Please answer the following questions in your own words.

1. What did you find most helpful about the classes?

2. What did you find least helpful about the classes?

3. Is there any information you would like to have added to the classes?