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Self-Reported Health Status and Sickle Cell Trait Knowledge in Young Adults with an African Heritage at a Large University in the Southeast

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SELF-REPORTED HEALTH STATUS AND SICKLE CELL TRAIT KNOWLEDGE IN YOUNG ADULTS WITH AN AFRICAN HERITAGE AT A LARGE UNIVERSITY IN THE SOUTHEAST

by

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A thesis submitted in fulfillment of the requirement for the Honors
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ABSTRACT

The purpose of this study is to survey self-reported health symptoms and knowledge of Sickle Cell Trait in young adults with an African heritage. The aim is to expand a comprehensive assessment system to measure factors associated with carrying the Sickle Cell Trait. Historically being a Sickle Cell Trait carrier was thought to be asymptomatic. However, current research has suggested this may not be true. While young adults may have greater knowledge of Sickle Cell Disease, little is known about their awareness of Sickle Cell Trait. Furthermore, no research on these topics have been conducted in young adults with African heritage (Latino/Hispanic, Caribbean, Multi-Racial, etc.). Measures of Sickle Cell Trait Carrier Awareness, Sickle Cell Trait Knowledge, and Physical Health Symptoms are presented from 54 young adults with African Heritage. The Hispanic and Multi-Racial participants reported lower awareness of their Sickle Cell Trait Carrier status compared to the African American participants. Hispanic and Multi-Racial participants reported lower Sickle Cell Trait Knowledge compared to the African American participants. All subjects demonstrated lower levels of Sickle Cell Trait Knowledge than would be expected given the potential health consequences.

Key words: Sickle Cell Trait, Sickle Cell Trait Knowledge, College Students, Multi-Racial

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INTRODUCTION

Sickle cell disease (SCD) affects millions of people throughout the world. Approximately 70,000 to 100,000 Americans have sickle cell disease, the most common form of an inherited blood disorder. Sickle cell disease is present in individuals at birth. It describes a group of disorders that affects hemoglobin, the molecule in red blood cells that delivers oxygen throughout the body (National Institutes of Health, 2012). Individuals with this SCD have atypical hemoglobin molecules called hemoglobin S, which can distort red blood cells into a sickle, or crescent, shape (National Institutes of Health, 2012) According to the Center for Disease Control and Prevention, it is inherited when a child receives two sickle cell genes—one from each parent, found on chromosome 11. Individuals who inherit one sickle cell gene and one normal gene have sickle cell trait (SCT). Historically it was thought that individuals with SCT do not have any symptoms of SCD, but they can pass the trait on to their children (Centers for Disease Control and Prevention, 2014).

Epidemiology of Sickle Cell Trait

Sickle cell trait affects 1 million to 3 million Americans. The sickle cell gene is most often found in African Americans; however, it also occurs in Hispanics, South Asians, Caucasians from southern Europe, and people from Middle Eastern countries. More than 100 million people worldwide have sickle cell trait (American Society of Hematology, 2018). The knowledge and awareness of carrier status is important because there are risks of having a child with sickle cell disease or a child who is a carrier. If both parents have SCT, there is a 50% chance that any child they produce also will have SCT. Such children will not have symptoms

commonly associated with SCD, but they can pass SCT on to their children. If both parents have SCT, there is a 25% chance that their child will have SCD. There is the same 25% chance that the child will not have SCD or SCT (Centers for Disease Control and Prevention, 2014). According to World Health Organization estimates, 5% of the global population carries the SCT. Eight to ten percent of African Americans are affected by SCT (American Society of Hematology, 2018).

Complications of Sickle Cell Trait

Historically SCT was not thought to have associated symptoms or complications. However, several complications associated with SCT have been recently identified. Specifically, associations of SCT have been found with renal disorders, muscle disorders, and sudden death syndrome. These include renal medullary cancer, hematuria (blood in the urine), renal papillary necrosis, hypothesnuria (reduced ability to concentrate urine), splenic infarction, exertional rhabdomyolysis (explosive muscle breakdown), and exercise-related sudden death (Tsaras, Owusu-Ansah, Boateng, & Amoateng-Adjepong, 2009).

Renal Dysfunction

Renal dysfunction is one of the most common complications associated with SCT. There are two different types of Renal disorders related to SCT. Renal medullary carcinoma is a rare, aggressive tumor of the kidney that is seen almost exclusively in young individuals with sickle cell trait (Tsaras et al., 2009). Renal medullary carcinoma grows rapidly in an infiltrative pattern and invades the renal sinuses, with nearly all patients dying of the disease within several months

after diagnosis (Watanabe, Billis, Guimarães, Alvarenga, de Matos, Cardinalli, & Suzigan, 2007).

Renal medullary tumor commonly affects the right kidney, and it tends to be lobulated, firm and poorly circumscribed (Watanabe et al., 2007). Also, another form of renal disease that is associated with SCT is renal papillary necrosis. Renal papillary necrosis presents with painless gross hematuria. The left kidney is more frequently involved primarily because of its larger size and the higher venous pressure from the compression of the left renal vein on the iliac crest between the aorta and the superior mesenteric artery (Tsaras et al., 2009). The hematuria associated with renal papillary necrosis is commonly managed conservatively with bed rest, intravenous hydration, and alkalization of the urine (McInnes, 1980). Renal dysfunction is commonly found in patients with SCT. In 2009 approximately 120 cases had been reported in total concerning the disease. Out of 120 only 1 patient was not positive for sickling status. Also, renal medullary is a male dominant disease for men under 24. But have equal frequency by gender after age 24 years (Tsaras et al., 2009). The origin of Renal medullary carcinoma is not quite understood. However, experience with radiographic and pathologic findings suggests that renal medullary carcinoma probably originates in the calyceal epithelium in or near the renal papillae, which could be the result of the chronic ischemic damage of the epithelium of the renal papillae related to sickled erythrocytes (Watanabe et al., 2007).

Splenic Infarcts

Splenic infarcts are an uncommon complication of sickle cell trait. Splenic infarcts can be caused by the environmental factors such as exposure to low oxygen tension at high altitudes,

including flight in unpressurized aircraft cabins or exercise in mountainous areas in those not acclimatized to such areas circumscribed (Tsaras et al., 2009). The presenting symptom is left upper-quadrant abdominal pain. Most cases of splenic infarction can be adequately treated with lowering altitude, sufficient hydration, and analgesia, although splenectomy may be needed in severe instances (Benenson et al., 2018). Splenic infarcts most likely affects men, non-black, patients with greater than 40% HBS at the time of incidence, and lowlanders who ascend to high altitude compared with native highlanders. In a previous study done in Colorado features 25 cases of splenic infarcts associated with SCT. All the male participants were symptomatic in the first 24 hours, on ascent to altitude higher than 2300 m (7500 ft). The results suggest a high likelihood for splenic syndrome in men of any ethnicity with left upper quadrant pain after exposure to moderate to high altitudes. The origin of Splenic infarct occurs due to sequestration of red cells resulting in an enlarged spleen, followed by splenic infarction caused by vaso-occlusion due to sickle cells. (Yanamandra Das, Malhotra, & Varma, 2018).

Sudden Death Syndrome

Exercise-related deaths, although rare, occur at higher rates in individuals with sickle cell trait (Tsaras et al., 2009). This is also known as sudden death syndrome and is sometimes termed exertional rhabdomyolysis (explosive muscle breakdown). This complication has been reported in military recruits and elite athletes when hypoxia within anaerobic skeletal muscles leads to massive sickling, multi-organ damage, and death (Benenson et al., 2018). Most of the cases of sudden exertional death (SED) in those with SCT have occurred during military basic training (Murray, & Evans, 1996). SCT affects an estimated 7–9% of non-Hispanic Blacks, 0.5% of Hispanics, to 0.2% of Whites in the U.S. general population versus 5.02% of non-Hispanic

Blacks, 1.08% of Hispanics, and 0.1% of Whites in the U.S. military (Singer, Chen, Shao, Goldsmith, Byrne, & Niebuhr, 2018). In recent years, there has been heightened attention on cases of athletes with sickle cell trait who have experienced exertion-related illness and, in some cases, sudden death, during or after strenuous athletic training sessions (American Society of Hematology, 2018).

Sickle Cell Knowledge

Sickle cell disease and SCT are diagnosed with a simple blood test (Centers for Disease Control and Prevention, 2014). Screening is typically performed to identify newborns with SCD so that appropriate care can be initiated as soon as possible. While screening for SCD, SCT carriers are also identified. Because detection of SCT is not the primary purpose of the newborn screening, some laboratories and hospitals may not convey the SCT finding directly to parents, and therefore, parents of children with SCT may be unaware of their infant's screening results (Benenson, Porter, & Vitale, 2018).

A recent survey found that more than one third of screening follow-up programs have no protocol in place that provides guidance for notification when infant tests are positive for SCT (Patricia, Jason, Bradford, Philippa, & Howard, 2008). Lack of knowledge could potently put the child at risk for complications and affect family planning later in life. Another study performed on adult participants found that many participants were uncertain of their own trait status (Harrison, Walcott, and Warner, 2017). A total of 5% of participants reported that they had SCT (n = 14), and 42% indicated that they did not have SCT (n = 108). However, 14% (n = 36) responded "I don't know," 36% (n = 94) responded "I don't think I do," and 2% (n = 6)

responded “I think I do.” Together, the three groups who indicated uncertainty about their personal trait status comprised 52% of the sample. The SCT Knowledge Questionnaire these researchers used in Appendix B. This was the only SCT Knowledge Questionnaire that could be identified.

ASCQ-ME

A comprehensive assessment system for SCD has been developed. The Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-ME), is a patient-reported outcome measurement system that assesses the physical, social, and emotional impact of SCD. The ASCQ-Me includes seven different measures. The measure is Emotional Impact, Pain Episode, Pain impact, The Sickle Cell Disease Medical History Checklist, Sleep Impact, Social Functioning Impact, and Stiffness impact. Although ASCQ-ME is used to measure patients with SCD, it does not apply to patients with SCT. The ASCQ-ME represents a model that may be used in the future for the developed for a comprehensive assessment system for SCT

Current Study Aims

The current study aims to survey self-reported health symptoms and knowledge of SCT in young adults with an African heritage. The purpose is to expand a comprehensive assessment system to measure SCT. Historically SCT was thought to be asymptomatic. However, current research has suggested this may not be true. While young adults may have knowledge of SCD, little is known about their awareness of SCT. Furthermore, no research on these topics have been conducted in young adults with African heritage (Latino/Hispanic, Caribbean, multi-racial, etc.).

Therefore, the present study aims to survey the health status, SCT knowledge, and SCT awareness of young adults that this may affect.

Hypotheses

I. African American participants will be more likely to know their SCT status than any other group with African Heritage.

II. African American participants will have higher SCT knowledge than any other group with African Heritage.

III. If enough participants with SCT respond to the survey, it is hypothesized that they will report more physical symptoms than those who do not carry the trait.

METHODS

Participants

Undergraduates enrolled in introductory psychology courses at a large university in the southeastern United States were recruited to participate in ongoing research surveying self-reported health symptoms and knowledge of SCT in young adults with an African heritage. The announcement for the study is listed in Appendix A. Participants received credit in the Introductory psychology course which is a required part of the general education curriculum for most majors at this university. Therefore, all college students and majors were well represented. Eligibility criteria excluded students with no African or Hispanic heritage. Participants had to be between the age of 18 and 25 years, and able to complete an online questionnaire in the English language. This study was reviewed as exempt by the UCF Institutional Review Board (IRB) and the letter stating this is presented in Appendix B.

Measures

Demographics Questionnaire. A 14-item background self-questionnaire to collect demographic information was constructed for this study which includes age, major, gender, racial or ethnic, health status, height, weight, classification in college and living status. This scale is included in Appendix C.

SCT Knowledge Questionnaire. This questionnaire will test the knowledge of Sickle Cell Trait. The participants were given 12 true or false questions about SCT. This scale was constructed by Harrison, Walcott, and Warner (2017) and is included in Appendix D. There is no currently available published reliability or validity data for this instrument. The internal

consistency (Chronbach's Alpha) of the SCT Knowledge Questionnaire items for the present sample was .83.

Cohen Hoberman Physical Symptom Questionnaire (CHIPS). This questionnaire measures of perceived severity and frequency of 33 common physical symptoms (Cohen & Hoberman, 1983). This scale is included in Appendix E. The participants rate a series of physical symptoms on how much a problem has bothered or distressed them during the past two weeks including today. All 33-items are answered on a five-point scale from 0 (not been bothered by the problem) to 4 (meaning the problem has been an extreme bother). Adequate reliability and validity for the scale has been reported in Allen, Wetherell, and Smith (2017).

Validity Check Questions (Vcheck). Three questions were included to assess whether participants responded in a random or careless manner. These questions were interspersed within Demographics Questionnaire and the SCT Knowledge Questionnaire. Participants were eliminated if they endorsed any of the items in the random or careless direction. The items are listed in Appendix F.

RESULTS

There were 88 total individuals who responded to the survey announcement and 28 participants were eliminated because they were from racial/ethnic groups without African heritage. Six subjects exceeded the VCheck item criteria for random/careless responding were also eliminated. The final study sample totaled 54 emerging adults between the age range of 18 and 25 (M=19.67, SD = 1.92) with 66.6% identifying as female. The survey took on average 17 minutes for participants to complete online. All respondents were single.

Participants were placed into three self-identified racial/ethnic groups, African American, Hispanic, and Multi-Racial based on their responses on the Demographic Questionnaire. Thirty-three participants self-identified as African American, 12 self-identified as Hispanic/Latino, and 9 self-identified as Multi-Racial. There were no age or sex differences between these groups when tested by ANOVA or Chi-Square. A greater percentage of the African American participants (33.3%) were Freshman compared to the Hispanic/Latino and Multi-Racial groups combined when tested by Chi-Square 8.478, df=3, p<.037. One of the participants in the Black group reported having SCD, and 3 in the African American group reported having SCT. The remainder of participants reported that they either did not have Sickle Cell Trait or did not know their diagnostic status.

Hypothesis 1: Group Differences in Sickle Cell Carrier Status Awareness

Based on previous literature, this study hypothesized that the groups will differ on their SCT carrier status awareness frequency with African American participants being significantly more aware if they carry the gene or not. This was assessed with the following question from the

Demographics questionnaire: “Have you been diagnosed with Sickle Cell Trait?” Twelve percent of the African American participants did not know their SCT carrier status as compared to 25% and 67 percent of the Hispanic and Multi-Racial groups, respectively. This finding is presented in Figure 1.

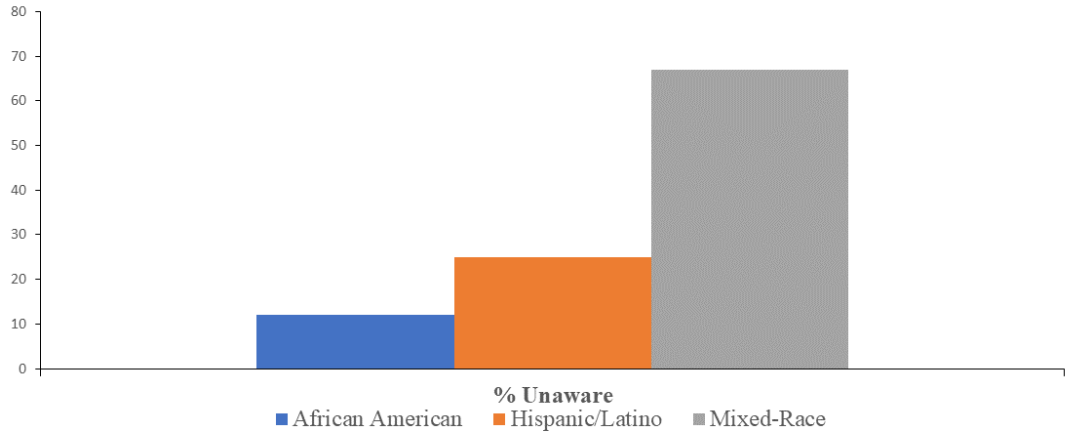

Figure 1: Sickle Cell Trait Status Awareness by Group

The 3 groups were tested with the Kruskal Wallis Test (a nonparametric test). There was a statistically significant difference between the number of subjects aware of the Sickle Cell Trait status between the different groups $H(2) = 11.332$, $p = .003$. Table 1 lists the Pairwise comparisons of the three groups.

Table 1

Pairwise Comparisons of Sickle Cell Status Awareness between the Groups

Sample 1-Sample 2	Test Statistic	Std. Error	Std. Test Statistic	Sig.
African American v. Hispanic	-5.148	4.235	-1.216	.224
African American v. Multi-Racial	-15.773	4.724	-3.339	.001
Hispanic v. Multi-Racial	-10.625	.539	-1.918	.055

Review of Table 1 indicates the African American group were aware of their trait status at significantly greater frequency than those from the Multi-Racial group. This difference approached significance for the comparison between the African Americans and Hispanic groups.

Hypothesis 2: Group Differences in Sickle Cell Trait Knowledge

Based on previous literature, this study hypothesized that the groups would differ on their mean SCT Knowledge levels with African American participants having significantly greater knowledge. The participants in the African American group scored 6.5 items correct, Hispanics scored 5.2 items correct, and the Multi-Racial group scored 3.9. These findings are presented in Figure 2.

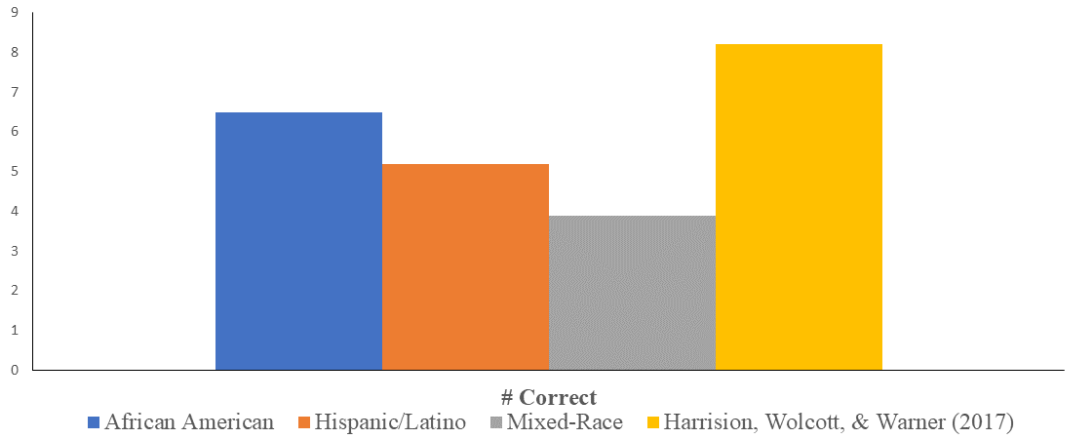

Figure 2: Sickle Cell Trait Knowledge Test Scores by Group

The SCT Knowledge scores were then compared with ANOVA. There was a statistically significant main effect for group on the SCT Knowledge total score, $F(2, 48) = 5.941$, $p < .01$, partial $\eta 2 = .198$ and observed power of .858. Post hoc Tukey pairwise comparisons were then conducted to evaluate how the groups differed from one another. The African American Group demonstrated significantly higher scores on the SCT Knowledge total score than the Multi-Racial group but not the Hispanic group. These results are summarized in Table 2.

Table 2

Comparison of Groups on Sickle Cell Trait Knowledge

	Mean (SD)			Main Effect			Post hoc tests		
Variables	**African American (n=32)**	**Hispanic (n=10)**	**Multi-Racial (n=9)**	**F**	**p**	**η^2**	**African American (v) Hispanic**	**African American (v) Multi-Race**	**Hispanic (v) Multi-Race**
SCTKtot	6.53 (2.37)	5.2 (1.69)	3.89 (1.45)	5.941	< 0.01	.198		*	

Note. Post-hoc comparisons were evaluated using Tukey's HSD and are marked according to the degree of significant difference. SCTKtot=Sickle Cell Trait Knowledge Total Score.
* $p < .05$.

Hypothesis 3: Sickle Cell Trait Carriers Will Report More Physical Symptoms

Sickle Cell Trait Carriers were hypothesized to report more physical symptoms than those who do not carry the trait. Unfortunately, only 3 participants reported knowing that they were SCT carriers. This low number precluded any statistical comparisons of physical symptoms between a SCT carrier group and non-carriers. For exploratory purposes, the individual responses of the 3 individual SCT Carriers were compared to the group average of all other participants (not including the one participant with SCD). Two of the 3 individual SCT carriers were females, and they were 18, 22, and 23 years of age. Of the 33 physical symptoms listed on the CHIPS, there was no individual symptom that all three of the SCT carrier individuals reported. Furthermore, no symptom area for any of the SCT carriers appeared to be elevated from the median response of non-carriers. The median response of non-carriers physical symptoms was 0 for all responses except item 9. Headaches, which was 1. The responses of the three Sickle Cell Carriers are summarized in Table 3 by item.

Table 3

Individual Sickle Cell Trait Carriers' Responses to the Cohen Hoberman Physical Symptom Questionnaire (CHIPS).

	SCT Carrier		
CHIPS Items	1	2	3
1. Sleep Problems	2	0	3
2. Weight Change	0	4	0
3. Back Pain	0	4	3
4. Constipation	2	0	0
5. Dizziness	0	2	0
6. Diarrhea	1	2	0
7. Faintness	0	2	0
8. Constant Fatigue	0	0	0
9. Headache	0	1	2
10. Migraine Headache	2	0	1
11. Nausea and/or vomiting	0	0	0
12. Acid Stomach or Indigestion	0	0	0
13. Stomach Pain	1	2	0
14. Hot or Cold Spells	0	0	0
15. Hands Trembling	0	0	0
16. Heart Pounding or Racing	0	0	0
17. Poor Appetite	0	3	0
18. Shortness of Breath	0	0	3

19. Numbness or Tingling	1	0	0
20. Felt Weak All Over	2	3	0
21. Pains in Heart or Chest	0	2	0
22. Feeling Low in Energy	2	0	0
23. Stuffy Head or Nose	0	0	3
24. Blurred Vision	1	2	1
25. Muscle Tension or Soreness	0	0	0
26. Muscle Cramps	0	0	0
27. Severe Aches and Pains	0	0	0
28. Acne	4	2	0
29. Bruises	0	0	0
30. Nosebleed	0	0	0
31. Pulled (Strained) Muscles	0	0	0
32. Pulled (Strained) Ligaments	0	0	0
33. Cold or Cough	0	0	0

Response Scale: 0-1=Not at all; 2=Several days; 3=More than half the days; 4=Nearly every day.
Median Response for Non-Carriers=0, Except for Item 9 which equaled 1.

DISCUSSION

In the current study, young adults with an African heritage participated in a survey that assessed awareness of the SCT carrier status, knowledge of SCT, and self-reported health symptoms. The ultimate purpose of this survey was to expand a comprehensive assessment system to measure SCT. As stated in the literature review, being knowledgeable of sickle trait status is important for individuals with African Heritage. This is particularly relevant to family planning and there is emerging evidence that sickle cell trait is not asymptomatic. But, to become knowledgeable of one's sickle cell trait status, genetic testing is required. Testing for SCT and SCD is routinely administered to African Americans in the United States. However, formal feedback of SCT status is not consistent. Furthermore, it is not clear the extent to which individuals with African heritage (many Hispanics and Multi-Racial) are routinely tested and provided feedback.

The first hypothesis was that African American participants will be more likely to know their status than any other group with African Heritage. As seen in Table 1, this first hypothesis was partially supported. That is, the African American group demonstrated significantly more awareness of their Sickle Cell Trait status than those from the Multi-Racial group. The difference between the African American and Hispanic groups was not significant, but the difference between the Hispanic and Multi-Racial groups approached significance (p.=.055), suggesting that Multi-Racial individuals were the least informed of any group.

The second hypothesis predicted African American participants would have higher SCT knowledge than the other two groups with African Heritage. As seen in Table 2, the findings

partially supported the hypothesis. The results showed African American demonstrated significantly higher scores on the SCT Knowledge Questionnaire than the Multi-Racial group, but not the Hispanic group. This demonstrates the lack of SCT knowledge in Multi-Racial individuals when compared to African Americans. Which proves individuals are unaware of the risks and complications of SCT. This can put an individual life at risk and affect family planning.

Finally, the third hypothesis stated if enough participants with SCT responded to the survey, they would report more physical symptoms than those who do not carry the trait. Unfortunately, an insufficient number of participants with SCT responded to the survey, and the third hypothesis could not be statistically analyzed. However, three participants did report that they had SCT. Visual inspection of Table 3 did not reveal any symptom pattern that the SCT carriers reported differently than the rest of the participants combined. That is, none of the symptoms of these three individuals appeared to be elevated from median response of Non-Carriers as a group.

The primary limitation of this study was the small sample size. Data was collected from the undergraduate subject pool for approximately two months. Even though there were up to 1000 students enrolled in eligible classes during this interval, the number of students with African American heritage was much less. In addition, college students cannot be viewed as representative of the population. Therefore, dues to the small sample size and the sample biases (higher SES and higher education), this study should be considered preliminary to larger efforts. Indeed, the sample collection is continuing for the next several semesters and the hope is that the findings will be reported in scientific journals.

Another primary limitation in this study was the difficulty in classifying racial and ethnic backgrounds. When it came to classifying Hispanic/Latino individuals, some participants self-identified as Hispanic/Latino, but then reported black grandparents. The approach taken here was to place individuals into the group they self-identified. Conversely, other participants self-identified as Multi-Racial reported only one black grandparent. Future studies may wish to modify the demographic section to add even more specificity in the reporting of racial and ethnic background. Another limitation discovered was having a category of Multi-Racial did not provide sufficient detail for analysis of African heritage because a general category of Multi-Race could include individuals with Asian, Native American, and Pacific Islander background. It is very difficult to understand the importance of sickle cell testing across races with so much variability in the groups. The simplest solution in the future may be to test all newborns for SCT status irrespective of the parents reported racial identity and then to have a clear mechanism to report these results so they are retrievable by the individual from their medical records.

In conclusion Sickle Cell Trait testing should be a routine part of post-natal care for all individuals without regard to race given the increasing complexity of racial heritage. While the concept of racial identify is essential to study socioeconomic and psychosocial variables, it is does not have the same level of utility when studying biological/disease variables such as SCT and SCD. The complexity of race is becoming too varied of a concept to guide medical treatment in the future.

APPENDIX A: STUDY ANNOUNCEMENT

UNIVERSITY OF CENTRAL FLORIDA

EXPLANATION OF RESEARCH

Title of Project: Self-Reported Health Status and Sickle Cell Trait Knowledge in Young Adults with an African Heritage at a Large University in the Southeast

Principal Investigator: Jeffrey E. Cassisi, Ph.D., Professor

Other Investigators: Vinkrya Ellison HIM student

Faculty Supervisor: Jeffrey E. Cassisi, Ph.D., Professor

You are being invited to take part in a research study. Whether you take part is up to you. Much is known about the effects of Sickle Cell Disease, a genetic condition that mostly effects people with an African heritage. Sickle Cell Disease is distinguished from a condition known as Sickle Cell Trait, Sickle Cell Trait describes a condition when a person carries the gene for Sickle Cell Disease, but doesn't have it fully expressed. Less is known about the effects of Sickle Cell Trait. The current study aims to survey self-reported health symptoms and knowledge of Sickle Cell Trait in young adults with an African heritage. The purpose is to expand a comprehensive assessment system to measure Sickle Cell Trait. Furthermore, few studies have been conducted on Sickle Cell Trait in young adults with African heritage (multirace, Latino/Hispanic Caribbean, etc.). Therefore, the present study aims to survey the health status, Sickle Cell Trait knowledge, and Sickle Cell Trait awareness of young adults who are at risk for this condition.

You will be presented with an online survey which will ask a series of questions measuring Sickle Cell Trait knowledge and Self-Reported Health Symptoms. You may take the survey on any computer you prefer. Please be assured that your responses will be kept in encrypted computer files in the Health Psychology Laboratory (PSY 205) and no identifying information will be collected. This online survey should take less than 1- hour to complete.

Your participation in this study is voluntary. You are free to withdraw your consent and discontinue participation in this study at any time without prejudice or penalty. Your decision to participate or not participate in this study will in no way affect your relationship with UCF, including continued enrollment, grades, employment or your relationship with the individuals who may have an interest in this study.

There is no foreseeable risk or discomfort to you by participating in this research. However, if participation in this research has raised any concern regarding your health, medical services at

the UCF Student Health Center are available to you as well. Please visit http://shs.sdes.ucf.edu/ for more information.

You must be 18 years of age or older and at risk for Sickle Cell Disease or Sickle Cell Trait to take part in this research study. This includes young adults with African heritage (multirace, Latino/Hispanic, Caribbean, etc.).

Individuals of American Indian or other Native American, Asian or Pacific Islander, Caucasian (other than Hispanic) individuals are not eligible to participate since Sickle Cell Disease or Sickle Cell Trait does not generally affect individuals of those race/ethnicities.

Study contact for questions about the study or to report a problem: If you have questions, concerns, or complaints, please contact:

- Vinkrya Ellison, HIM student, Department of Psychology by email at Kay25@Knight.ucf.edu
- Dr. Jeffrey E. Cassisi, Faculty Supervisor, Department of Psychology by email at Jeffrey.Cassisi@ucf.edu

IRB contact about your rights in this study or to report a complaint: If you have questions about your rights as a research participant, or have concerns about the conduct of this study, please contact Institutional Review Board (IRB), University of Central Florida, Office of Research, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246 or by telephone at (407) 823-2901, or email irb@ucf.edu.

APPENDIX B: IRB NOTICE OF EXEMPTION

UNIVERSITY OF CENTRAL FLORIDA

Institutional Review Board
FWA00000351
IRB00001138, IRB00012110
Office of Research
12201 Research Parkway
Orlando, FL 32826-3246

EXEMPTION DETERMINATION

March 3, 2020

Dear Jeffrey Cassisi:

On 3/3/2020, the IRB determined the following submission to be human subjects research that is exempt from regulation:

Type of Review:	Initial Study
Title:	Self-Reported Health Status and Sickle Cell Trait Knowledge in Young Adults with an African Heritage at a Large University in the Southeast
Investigator:	Jeffrey Cassisi
IRB ID:	STUDY00001354
Funding:	None
Grant ID:	None
Documents Reviewed:	• HRP-251 - FORM - Faculty Advisor Review.pdf, Category: Faculty Research Approval; • IRB Cassisi 1354 HRP-254-FORM-Explanation_of_Research_v 3.3.20.pdf, Category: Consent Form; • IRB Cassisi 1354 IRB Ellison HRP-255-FORM-RequestforExemption (3-3-20).docx, Category: IRB Protocol; • SCT measures.docx, Category: Test Instruments;

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made, and there are questions about whether these changes affect the exempt status of the human research, please submit a modification request to the IRB. Guidance on submitting Modifications and Administrative Check-in are detailed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Kamille C. Birkbeck

Kamille Birkbeck
Designated Reviewer

APPENDIX C: DEMOGRAPHICS QUESTIONNAIRE

Demographics Questionnaire

The following questions will ask you about your background. Please read each question carefully and then select the answer that best describe you.

D1 How old are you? (in years)

_____

D2 What is your sex?

o Male (1)

o Female (2)

o other (3) _____

D3 What is your racial or ethnic identification?

o American Indian or other Native American (1)

o Asian or Pacific Islander (2)

o Black or African American (3)

o Caucasian (other than Hispanic) (4)

o Mexican-American (5)

o Puerto Rican (6)

o Other Hispanic (7) _____

o Other (8) _____

D4 Which of your biological parents or biological grandparents are black? (Check all that apply)

▢ Mother (1)

▢ Father (2)

▢ Maternal Grandmother (Mom's mother) (3)

▢ Maternal Grandfather (Mom's father) (4)

▢ Paternal Grandmother (Dad's mother) (5)

▢ Paternal Grandfather (Dad's father) (6)

D5 What is your marital status?

- o Married (13)
- o Widowed (14)
- o Divorced (15)
- o Separated (16)
- o Never married (17)

D6 What is your classification in college?

- o Freshman/First Year (20)
- o Sophomore (21)
- o Junior (22)
- o Senior (23)
- o Graduate Student (24)
- o Unclassified (26)

D7 How tall are you without shoes?

D8 How much do you weigh, in pounds (lbs)?

D9 Are you a smoker? (this includes e-cigarettes & vape pens)

- o Yes (1)
- o No (2)
- o Ex-Smoker (3)

D10 Have you been diagnosed with Sickle Cell Trait?

- o Yes (1)
- o No (2)
- o I do not know (3)

D11 Have you been diagnosed with Sickle Cell Disease?

- o Yes (1)
- o No (2)

o I do not know (3)

APPENDIX D: SCT KNOWLEDGE QUESTIONNAIRE

The following questions will ask you about your knowledge of Sickle Cell Trait. Please read each question carefully and then select true or false based on what you know about Sickle Cell Trait.SCTKQ1 Sickle Cell Trait can turn into Sickle Cell Disease

- o True (1)
- o False (2)
- o I do not know (3)

SCTKQ2 If a person has Sickle Cell Trait, it can be passed on to his or her children

- o True (1)
- o False (2)
- o I do not know (3)

SCTKQ3 Sickle Cell Trait often causes pain crises

- o True (1)
- o False (2)
- o I do not know (3)

SCTKQ4 People with Sickle Cell Trait have inherited a gene for sickle hemoglobin from one parent but not the other

- o True (1)
- o False (2)
- o I do not know (3)

SCTKQ5 People with Sickle Cell Trait who are athletes such as football players may be at risk of sudden death

- o True (1)
- o False (2)
- o I do not know (3)

SCTKQ6 Most people with Sickle Cell Trait live long, healthy lives

- o True (1)
- o False (2)
- o I do not know (3)

SCTKQ7 If a person has Sickle Cell Trait, all his or her children will have Sickle Cell Trait

o True (1)

o False (2)

o I do not know (3)

SCTKQ8 Sickle Cell Trait is only passed down through the mother

o True (1)

o False (2)

o I do not know (5)

SCTKQ9 People from all racial/ethnic backgrounds can be affected by Sickle Cell Trait

o True (1)

o False (2)

o I do not know (3)

SCTKQ10 All states in the United States screen newborns babies for Sickle Cell Trait as well as other conditions

o True (1)

o False (2)

o I do not know (3)

SCTKQ11 Sickle Cell Trait causes many medical problems

o True (1)

o False (2)

o I do not know (3)

SCTKQ12 Sickle Cell Trait results many more deaths each year than Sickle Cell Disease

o True (1)

o False (2)

o I do not know (3)

APPENDIX E: COHEN HOBERMAN PHYSICAL SYMPTOM QUESTIONNAIRE

Mark the number for each statement that best describes HOW MUCH THAT PROBLEM HAS BOTHERED OR DISTRESSED YOU DURING THAT PAST TWO WEEKS INCLUDING TODAY. Mark only one number for each item. At one extreme, 0 means that you have not been bothered by the problem. At the other extreme, 4 means that the problem has been an extreme bother. HOW MUCH WERE YOU BOTHERED BY:

1. Sleep problems (can't fall asleep, wake up in middle of night or early in morning)
2. Weight change (gain or loss of 5 libs. or more)
3. Back pain
4. Constipation
5. Dizziness
6. Diarrhea
7. Faintness
8. Constant fatigue
9. Headache
10. Migraine headache
11. Nausea and/or vomiting
12. Acid stomach or indigestion
13. Stomach pain (e.g., cramps)
14. Hot or cold spells
15. Hands trembling
16. Heart pounding or racing
17. Poor appetite
18. Shortness of breath when not exercising or working hard
19. Numbness or tingling in parts of your body
20. Felt weak all over
21. Pains in heart or chest
22. Feeling low in energy
23. Stuffy head or nose

24. Blurred vision
25. Muscle tension or soreness
26. Muscle cramps
27. Severe aches and pains
28. Acne
29. Bruises
30. Nosebleed
31. Pulled (strained) muscles
32. Pulled (strained) ligaments
33. Cold or cough

APPENDIX F: VALIDITY CHECK QUESTIONS (Vcheck)

WITHIN THE STANDARD DEMOGRAPHICS SECTION

V01 Are you between the age of 18 and 25?

o Yes (1)

o No (0)

V02 For this item, please select No

o Yes (0)

o No (1)

WITHIN THE SCT KNOWLEDGE QUESTIONNAIRE SECTION

V03 For this question, please select the "False" option

o True (0)

o False (1)

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