Implementation of the NCAA Sickle Cell Trait Screening Policy: A Survey of Athletic Staff and Student-athletes

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Abstract: Objective: To describe the perspectives and experiences of athletic trainers, coaches, and student-athletes approximately three years post-implementation of the NCAA sickle cell trait (SCT) screening policy.

Participants: Two-hundred and eight student-athletes, 32 athletic trainers, and 43 coaches from 10 NCAA Division I (DI) institutions in North Carolina from January to June 2014.

Methods: Two online surveys were used to assess knowledge, perspectives, and experiences.

Results: Athletic staff were more supportive than student-athletes of the need for the policy. Noted challenges included variation in implementation and follow-up for SCT-positive athletes, financial costs to institutions and athletes, and timing of the screening.

Conclusions: More education about SCT is needed for student-athletes and athletic staff in order to help make the implementation more successful. All parties need to be in agreement regarding the importance of knowing which student-athletes have SCT and how that information will be utilized.

Keywords: Athletics■Health education■Sickle cell trait■Pre-participation examination■Genetic counseling■Clinical medicine■Sports medicine

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INTRODUCTION

In the United States, more than three million people have sickle cell trait (SCT), which is characterized by the inheritance of one copy of the normal beta-globin gene and one copy of the sickle variant (HbAS).[1] SCT is common among, but not limited to, people with ancestors from Sub-Saharan Africa, the Mediterranean basin, India, the Arabian Peninsula, the Caribbean, South and Central America.[2–5] Although most carriers of SCT live with few or no health complications, studies indicate that physical exertion, altitude, and heat can have significant implications for their health.[3] SCT may be a risk factor for hematuria, exertional rhabdomyolysis, splenic infarction, and sudden death in people participating in rigorous and intense exercise.[3,4,6,11] Studies reveal that athletes in particular can experience elevated risks related to SCT when they are exposed to such extreme conditions during practice and play.[3,4,6,9]

NCAA universal precautions

In 2006, Dale Lloyd II, a freshman Rice University football player, died of apparent acute exertional rhabdomyolysis linked to SCT.[13] As a result of a wrongful-death lawsuit settlement between the Lloyd family, the National Collegiate Athletic Association (NCAA) and Rice University, the university and Conference USA submitted a recommendation to the NCAA for a mandatory SCT screening program.[2,13,14] The NCAA Committee on Competitive Safeguards and Medical Aspects of Sports Council welcomed the proposal and recommended that all member colleges and universities screen student-athletes whose sickle cell carrier status was not known.[2,13–15] Just prior to this, in 2007, the National Athletic Trainers' Association (NATA) and the College of American Pathologists (CAP) made the same recommendation.[2,16,17] The NCAA Division I (DI) Legislative Council adopted the policy in 2010, requiring that all DI student-athletes a) be tested for SCT, b) have prior proof of testing, or c) sign a liability waiver to decline the testing.[2,15,16] The Division

II (DII) Management Council implemented the measure in 2012,[18] and Division III (DIII) schools followed in 2013.[19] The screening could identify between 400 and 500 student-athletes with SCT each year and provide an opportunity to establish precautionary measures.[2]

The NCAA policy has been controversial, with dissenters citing ethical, legal, and social concerns about unintended effects of the policy.[14–16,18,21,22] Opponents of the policy argue that the disparate impact on black athletes inherent in the legislation not only calls into question protection from discrimination and stigmatization under Title VI of the Civil Rights Act of 1964, but also defeats the purpose of the policy by allowing some athletes to opt out who perceive themselves as targets or as immune from SCT because they are not black.[2,4,5,7,12,16,23] Many scientists, healthcare providers, and scholars question the necessity of a mandatory sickle cell screening program at NCAA schools.[7,8,10,16,24,25] In 2010, the Secretary of the U.S. Department of Health and Human Services' Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) reported that while they agreed with organizations such as the NCAA and NATA that protecting the health of collegiate athletes was important and that everyone should have the "opportunity to find out whether or not they have sickle cell trait", the committee could not recommend universal screening because it was not backed by scientific evidence.[16] Additionally, both the American Society of Hematology (ASH) and the Sickle Cell Disease Association of America (SCDAA) have advocated for universal precautions to reduce dehydration and strenuous exercise to protect all athletes from exertion-related illness.[26–28]

Purpose of the study

Although the NCAA created the policy in an effort to ensure the safety of student-athletes, implementation methods across the nation are largely unknown. Information about current implementation practices is crucial to enlighten all stakeholders about the effectiveness and implications of the policy, and to facilitate decision-making regarding the future implementation of the program. The purpose of this study is to describe the knowledge, perspectives, and attitudes of student-athletes, coaches, and athletic trainers (ATs) regarding the NCAA SCT policy at DI colleges and universities in North Carolina.

METHODS

Subject selection and recruitment

Athletic directors at the 18 NCAA DI institutions in North Carolina were contacted to determine their interest in their schools' participation in the study. Ten responded positively. A contact at each institution then emailed all their coaches, ATs, and student-athletes with an invitation to participate and a link to the survey. The study included all student-athletes, coaches, and ATs at the participating schools who completed the survey and were affiliated with a recognized NCAA DI sport.

Instruments and data collection

Separate surveys for athletic staff (coaches and ATs) and student-athletes were developed to collect information on demographics, knowledge of SCT, perspectives and implications of, and experience with the policy. Both surveys included three open-ended questions about perceived benefits, challenges, and concerns about the policy. Draft surveys were piloted with two athletic staff members and 50 student-athletes at one institution to determine if the questions were easy to understand, arranged in logical order, and would elicit the information needed. Formal surveys were administered through SurveyMonkey, Inc (Palo Alto, CA) between January and June 2014. The IRB at Duke University approved the study.

Data analysis and management

Responses were combined from three standardized but optional questions on respondents' race and ethnicity to create six race/ethnicity categories: white non-Hispanic, black non-Hispanic, other non-Hispanic, white Hispanic, black Hispanic, and other Hispanic.[29] Missing responses for sex for student-athletes were imputed using the sport played. Descriptive statistics were performed using SAS 9.3 (Cary, NC). Student-athlete information was stratified by SCT status. Text responses were analyzed from the three open-ended questions manually. No personally identifiable or institutional information was disclosed.

RESULTS & DISCUSSION

Demographics

Two hundred and eight (208) eligible student-athletes completed the survey (Table 1). Respondents represented the following sports: baseball, basketball, bowling, cross country, fencing, field hockey, football, golf, lacrosse, rowing, soccer, softball, swimming and diving, tennis, track and field, volleyball, and wrestling. Forty-three (43) coaches and 32 ATs were included in the analysis (Table 2). Respondents coached or served as ATs for the same sports as student-athletes except for bowling.

Knowledge

Seventy-five percent (75%) of the student-athletes reported that they were knowledgeable about the policy prior to the survey but most (59%) had not heard about any SCT-related deaths in student-athletes.

Table 1. Demographics of student-athlete study population (N = 208)[a].

	All (N = 208)[b]		SCT (N = 13)[b]	
	N (%)	Mean ± SD	N (%)	Mean ± SD
Age	151	20.0 ± 1.4	11	19.9 ± 1.4
Sex	208		11	
Female	120 (57.7)		6 (54.6)	
Male	88 (42.3)		5 (45.5)	
Race[c]	208			
White Non-Hispanic	93 (62.4)		1 (9.1)	
Black Non-Hispanic	38 (25.5)		10 (90.9)	
Other Non-Hispanic	4 (2.7)		0 (0.0)	
White Hispanic	9 (6.0)		0 (0.0)	
Black Hispanic	2 (1.3)		0 (0.0)	
Other Hispanic	3 (2.0)		0 (0.0)	
Classification	151		11	
Freshman	32 (21.2)		2 (18.2)	
Sophomore	48 (31.8)		2 (18.2)	
Junior	36 (23.8)		4 (36.4)	
Senior	32 (21.2)		3 (27.3)	
Graduate	3 (2.0)		0 (0.0)	
Transfer	152		11	
Yes	16 (10.5)		3 (27.3)	
No	136 (89.5)		8 (72.7)	

SCT, Sickle Cell Trait.
[a]Percentages represent the percentage of respondents for each question not the total number of study participants.
[b]Percentages may not add to 100% of the totals due to rounding.
[c]As defined by 2010 U.S. OMB categories.

Most coaches (74%) and all ATs regarded themselves as knowledgeable about SCT and sickle cell disease (SCD) and knew of previous reports of SCT-related student-athlete deaths prior to the NCAA SCT screening policy. Forty-eight percent (48%) of coaches and 97% of ATs agreed that people could not develop SCT as they aged, but some responded that SCT could turn into SCD (ATs 20%; coaches 62%). Coaches (71%) and ATs (100%) agreed that people who identify as white can have SCT.

Perspectives

Perspectives on the SCT screening policy and its effects varied widely among student-athletes (Table 3). Sixty-three percent (63%) supported the idea of required screening. Many felt strongly that the screening should be mandatory regardless of race/ethnicity (66%) or sport (71%). Self-identified white student-athletes felt they had no risk for SCT and should be exempt from screening. Thirteen percent (13%) of student-athletes felt that non-black student-athletes did not have to be concerned with testing. Several student-athletes specifically stated that they were not at risk and should not have been tested because they were "not black", because "I'm white, I can't get it", because there were "people historically immune to it", or that a physician had told them they did not "fit the demographic" of people who could get SCT. Another student indicated that because people would know their SCT status by the time they attended college, the testing was unnecessary.

Other students expressed concerns about the potential for decreased playing time. As one student-athlete said:

> I am concerned that individuals who find out they have SCT will be treated differently by coaches and trainers,

Table 2. Demographics of coach and athletic trainer study population (N = 75)[a].

	Coach		Athletic Trainer	
	N (%)[b]	Mean ± SD	N (%)[b]	Mean ± SD
Age	34	39.6 ± 8.7	30	32.8 ± 6.8
Sex	35		30	
Female	10 (28.6)		16 (53.3)	
Male	25 (71.4)		14 (46.7)	
Race[c]	34		30	
White Non-Hispanic	24 (70.6)		23 (76.7)	
Black Non-Hispanic	6 (17.7)		1 (3.3)	
Other Non-Hispanic	2 (5.9)		1 (3.3)	
White Hispanic	1 (3.0)		1 (3.3)	
Black Hispanic	0 (0.0)		1 (3.3)	
Other Hispanic	2 (5.9)		3 (10.0)	
Education Level	36		30	
Bachelor's or Technical Degree	19 (52.8)		3 (10.0)	
Graduate/Professional Degree	17 (47.2)		27 (90.0)	
Sport Affiliation	43		32	
Men's Only	17 (39.5)		10 (31.3)	
Women's Only	21 (48.8)		7 (21.9)	
Both	5 (11.6)		15 (46.9)	

[a]*Percentages represent the percentage of respondents for each question not the total number of study participants.*
[b]*Percentages may not add to 100% of the totals due to rounding.*
[c]*As defined by 2010 U.S. OMB categories.*

who may think they are not able to handle the athletic load that is required of DI athletes.

Table 4 describes the perspectives of coaches and ATs regarding the policy. The majority of coaches (92%) and all ATs found it beneficial to know the SCT status of student-athletes. Most coaches (81%) and ATs (87%) disagreed that student-athletes with SCT would be treated any differently other than necessary changes to workouts.

A common concern about the policy was the financial cost to the athletic department and student-athletes. Some respondents indicated their institution paid for the testing and some indicated that student-athletes had to pay.

Another concern was time lost from practice while waiting for test results. As one coach commented, "I don't like withholding players from practice until the test results come back − I might [withhold] … from conditioning workouts or testing but not from technically oriented practices".

Some coaches (67%) and ATs (47%) felt parents and guardians should be involved in the screening process. There were mixed responses regarding discrimination from the policy. One AT noted that it is because of the "fear [of] being accused of discrimination that we require athletes that have a statistically low chance of having sickle cell [trait] to be tested". Other ATs indicated that it was impossible to know everyone's genetic background, so testing everyone was the best route. Some coaches and ATs did not approve of offering a waiver; they thought all student-athletes should be tested. One coach stated "[it] should have been a rule earlier".

Experiences

Some student-athletes did not know whether they had been tested (22%) or indicated they had not been (10%) offered SCT screening by their athletic departments. After screening, 35% of student-athletes wanted to know more about the reasons for screening and 23% of student-athletes who tested negative for SCT wanted to know more about SCT.

Twenty-eight percent (28%) of coaches, but no ATs, reported that at least one student-athlete at their

Table 3. Perspectives of student-athlete study population with and without SCT[a].

	All (N = 208)[b]		SCT (N = 13)[b]		No SCT (N = 195)[b]	
	N	%	N	%	N	%
I support the NCAA sickle cell trait mandate.	153		11		142	
Strongly Agree/Agree	95	62.1	10	90.9	85	59.9
Neutral	45	29.4	1	9.1	44	31.0
Strongly Disagree/Disagree	13	8.5	0	0.0	13	9.2
Athletes at our school are well educated about the sickle cell trait screening before it occurs.	152		11		141	
Strongly Agree/Agree	25	16,4	3	27.3	22	15.6
Neutral	62	40.8	2	18.2	60	42.6
Strongly Disagree/Disagree	65	42.8	6	54.5	59	41.8
It would be helpful for me to have more information and education about sickle cell trait.	153		11		142	
Strongly Agree/Agree	62	40.5	8	72.7	54	38.0
Neutral	62	40.5	3	27.3	59	41.6
Strongly Disagree/Disagree	29	19.0	0	0.0	29	20.4
Sickle cell trait screening should be targeted to athletes based on race/ethnicity.	153		11		142	
Strongly Agree/Agree	25	16.3	3	27,3	22	15.5
Neutral	37	24.2	1	9.1	36	25.4
Strongly Disagree/Disagree	91	59.5	7	63.6	84	59.2
Athletes with sickle cell trait may be treated differently by peers or staff, outside of necessary adjustment to workouts.	153		11		142	
Strongly Agree/Agree	18	11.8	0	0.0	18	12.7
Neutral	43	28.1	4	36.4	39	27.5
Strongly Disagree/Disagree	92	60.1	7	63.6	85	59.9
Sickle cell trait screening should be targeted to athletes based on sport.	152		11		141	
Strongly Agree/Agree	10	6.6	2	18.2	8	5.7
Neutral	33	21.7	1	9.1	32	22.7
Strongly Disagree/Disagree	109	71.7	8	72.7	101	71.6
Parents or legal guardians should be involved in the screening process.	153		11		142	
Strongly Agree/Agree	50	32.7	8	72.7	42	29.6
Neutral	66	43.1	3	27.3	63	44.4
Strongly Disagree/Disagree	37	24.2	0	0.0	37	26.1

SCT, Sickle Cell Trait.

[a]*Percentages represent the percentage of respondents for each question not the total number of study participants.*

[b]*Percentages may not add to 100% of the totals due to rounding.*

Table 4. Perspectives of coach and athletic trainer study population (N = 75)[a].

	Coaches		Athletic trainers	
	N	%[b]	N	%[b]
I support the NCAA sickle cell trait mandate.				
Strongly Agree/Agree	28	77.8	26	86.7
Neutral	7	19.4	5	16.7
Strongly Disagree/Disagree	1	2.8	0	0.0
Athletes at our school are well educated about the sickle cell trait screening before it occurs.				
Strongly Agree/Agree	13	36.1	14	46.7
Neutral	15	41.7	8	26.7
Strongly Disagree/Disagree	8	22.2	8	26.7
The screening mandate has been disruptive to our program				
Strongly Agree/Agree	2	5.6	4	13.3
Neutral	9	25.0	1	3.3
Strongly Disagree/Disagree	25	69.4	25	83.3
It would be helpful for me to have more information and education about sickle cell trait.				
Strongly Agree/Agree	19	54.3	9	30.0
Neutral	14	40.0	14	46.7
Strongly Disagree/Disagree	2	5.7	7	23.3
Sickle cell trait screening should be targeted to athletes based on race/ethnicity.				
Strongly Agree/Agree	2	5.6	1	3.3
Neutral	7	19.4	3	10.0
Strongly Disagree/Disagree	27	75.0	26	86.7
Athletes with sickle cell trait may be treated differently by peers or staff, outside of necessary adjustment to workouts.				
Strongly Agree/Agree	2	5.6	2	6.7
Neutral	5	13.9	2	6.7
Strongly Disagree/Disagree	29	80.6	26	86.7
Sickle cell trait screening should be targeted to athletes based on sport.				
Strongly Agree/Agree	1	2.8	0	0.0
Neutral	5	13.9	6	20.0
Strongly Disagree/Disagree	30	83.3	24	80.0
Parents or legal guardians should be involved in the screening process.				
Strongly Agree/Agree	24	66.7	14	46.7
Neutral	7	19.4	7	23.3
Strongly Disagree/Disagree	5	13.9	9	30.0

NCAA, National Collegiate Athletic Association.
[a]*Percentages represent the percentage of respondents for each question not the total number of study participants.*
[b]*Percentages may not add to 100% of the totals due to rounding.*

institution had been removed from activity because of concern of developing a dangerous SCT-related condition. Many coaches (50%) and ATs (70%) reported that their student-athletes shared some information about their SCT screening results with them. Roughly half of coaches (45%) and ATs (53%) noted that parents were involved with the SCT screening process at one or more levels.

Forty-four percent (44%) of coaches and 13% of ATs did not alter practice, competition, or conditioning sessions for student-athletes with SCT. Among coaches that did make changes, 49% monitored the student-athletes more closely, 28% modified workouts or conditioning sessions, and 16% increased hydration for the student-athletes. Among ATs that did make changes, 78% monitored the student-athletes more closely, 63% modified workouts or conditioning sessions, and 72% increased hydration for the student-athletes. Two ATs removed student-athletes who were struggling or allowed them to move at their own pace. One AT reduced playing time for an athlete with SCT.

Student-athletes with SCT

Thirteen (13) student-athletes in the survey population were SCT positive (Table 1). Four, including a self-identified white student, found out about their status through the required screening and were at institutions that did not allow student-athletes to opt out of the screening. Almost all student-athletes with SCT said that more education and information about SCT would be helpful to them. Eight student-athletes felt parents should be involved in the screening process, however the survey did not ask how parents should be involved.

All student-athletes with SCT (13) reported informing the athletic staff of their results but none reported concerns with having to do so. Student-athletes discussed results with their teammates (eight) and significant others (nine). The four that learned their status through the NCAA policy were notified in person (two), by email (one), and by mail (one). All four had questions about SCT and the implications of their positive status, but only one received genetic counseling.

Of the 13 student-athletes with SCT, three reported personally modifying their workouts and conditioning sessions and two reported that these modifications were done by athletic staff. Four reported increasing their own hydration and four others reported that the athletic staff increased their hydration. Three reported paying more attention to signs and symptoms. Of the four student-athletes that learned of their positive trait status through the NCAA policy, two increased their hydration on their own while two changed the way they played their sport by modifying their workouts and conditioning, increasing their hydration, and/or being monitored more closely by staff. Eight student-athletes with SCT reported that athletic staff changed nothing due to their SCT status. None reported reduced playing time as a result of their status.

The primary benefits of the screening policy identified by student-athletes with SCT was that it created awareness among athletic staff and student-athletes that could help avoid adverse outcomes and could offer information for future family planning. Student-athletes without SCT also identified benefits such as awareness of potential health issues among teammates, reducing stereotypes related to who can have SCT, and that everyone is required to participate in the policy.

Discussion

The present study examined the knowledge, perspectives, and experiences of coaches, ATs, and student-athletes at DI institutions in North Carolina three years after implementation of the SCT screening policy. Team physicians and head ATs were also interviewed to get a more complete picture of how the institutions have been implementing the policy.[30]

The current study revealed that student-athletes responding to the survey supported the screening policy, but some were concerned about effects of screening, particularly the potential of discrimination for those that tested positive. Primary concerns of student-athletes pre-implementation, such as loss of scholarships or playing time, did not come to fruition, but remained concerns due to the lack of explanation by athletic staff of the implications of being a student-athlete with SCT. Similar to other studies, this study did not uncover discrimination against student-athletes who tested positive for SCT.[31] Nonetheless, several important issues surfaced that need to be addressed including who should be screened, variation in screening practices, costs, and education.

Who should be screened?

Some white student-athletes resented being required to be screened for SCT. They felt that only black student-athletes should be screened because they were the only ones at risk. Unlike recent discussions and practices by some athletic departments prior to the policy,[20,27,32,33] most student-athletes and the majority of the coaches and ATs did not support screening specific groups based on race/ethnicity/sport, as they felt it would foster discrimination. Though some respondents did support targeted screening, not everyone had accurate knowledge of who is at risk for SCT. Of the four student-athletes in this study who discovered their positive SCT status through the NCAA policy, one identified as white. If the policy were targeted based on race/ethnicity, this student would have been missed, and would still face the same heat- or exertion-related effects as black student-athletes with SCT.

In addition to the majority of the study participants, universal screening is also supported by many SCD/SCT experts, as estimates show that the NCAA policy would identify approximately 530 new cases of SCT each year

and that 11% would not be black or not identify as black.[27] The present study included only 208 student-athletes at 10 DI institutions. Four student-athletes were identified who found out their positive SCT status through required screening. Based on these findings, it is predicted that a survey of all NCAA student-athletes at the DI level nationwide may support these estimates[27] at or under the correct number of SCT positive student-athletes.

Variation in implementation practices and costs

Consistent screening methods and policies would allow for a more precise estimate of the number of SCT positive student-athletes. Responses from participants revealed considerable variation in how the policy was applied at different institutions. Some institutions required screening for all student-athletes and implemented it in a non-disruptive manner. Other institutions held student-athletes out of athletic activities while waiting for test results or even required that the student-athletes pay for the testing themselves. Financial cost is a valid concern[27,31,32] and the cost of screening as well as the test used, varied by institution. As predicted by Tarini et al.,[27] some athletic departments transferred the test cost to the students. If students cannot afford the test themselves, and therefore cannot participate in their sports, this could result in discrimination against student-athletes from low-income households. If institutions were using less costly and less specific tests such as Sickledex™, they may not have been correctly identifying student-athletes with SCT, thereby negating the point of the policy. Amidst the debate about whether less expensive tests are sufficient for mass screening, some major organizations are still not fully supportive of mass screening of student-athletes for SCT.[7,34–36]

At some institutions, athletes had delayed participation in their sport due to lack of sickle cell test results. This led to unanticipated alterations to coaching plans. Coaches indicated that there were sport-related activities that the athlete could have participated in without being at physical risk but these activities were not permitted due to institutional guidance related to the policy. Further inquiries into what types of activities these are, appropriate deadlines for test/practice logistics, and how both of these might be integrated into each institution's protocol could be a benefit to helping improve the implementation of the SCT policy.

The variation in procedures during athletic activities for athletes who tested positive for SCT also raised some questions and possible concerns. While some student-athletes with SCT and/or athletic staff took steps to reduce adverse outcomes in those student-athletes, the majority of student-athletes with SCT reported that the athletic staff did not make any changes in response to their SCT status. Further research is needed to determine whether a lack of change reflects negligence or indicates that these athletic staff and their respective schools had been implementing universal precautions.

Education

The success of any screening program is largely dependent on the target population understanding the importance of the screening and that the screening leads to some benefit(s) for those screened. According to the NCAA,[37] student-athletes were to gain knowledge that helps them know when to rest, hydrate, modify, reduce or halt activity to prevent health problems. The results of this study indicate that while student-athletes felt the testing was important and could help protect them, they did not receive enough education prior to or after screening to fully understand the ramifications of the screening or what the results could mean in the short or long term. The need for better SCT-related health education could be addressed with programs, resources, or partnerships with counselors, sickle cell centers, or other entities capable of providing this education, which is vital for increasing positive outcomes for student-athletes with SCT.[31,32]

Strengths

While there had been recent studies on knowledge and perspectives about SCT screening in NCAA institutions prior to the SCT policy,[20,27,31–33] this was believed to be the first published study investigating knowledge, experience and perspectives of student-athletes, coaches and ATs post-policy implementation. The online survey method provided anonymity for respondents and the survey could be completed on their own time.

Limitations

This study had a relatively low response rate (6% percent for student-athletes, 29% for coaches, and 57% for ATs), and the respondents represented only 10 of 18 DI schools in NC. This data may not be representative of all NCAA DI student-athletes, coaches, and ATs. The small number of respondents made it difficult to rely on statistical significance when comparing groups. A much larger national sample would produce more reliable data. There is no validated questionnaire or scale for SCT knowledge.

Lessons learned

Preliminary discussion with key personnel in all three sample groups would have provided a clearer sense of the viable sample needed for the study and may have improved recruitment strategies and thus, the information received. This

study used methods similar to those used by other researchers.[31,32] However, instead of a more rigorous sampling method and population selection, a more diverse population was included and therefore this study still contributes to the science on detection and management of SCT in athletes.

Conclusions

To date, executing the NCAA SCT policy has apparently not resulted in some of the concerns voiced by student-athletes and their advocates prior to implementation, such as loss of scholarships or playing time. Implementation varied among the schools, which led to several differences in experiences related to the policy. Increased education about SCT is needed for all involved, especially for SCT positive student-athletes. All parties, from the athletic and university administration to the student-athletes and their parents, need to be in agreement regarding the importance of knowing which student-athletes have SCT and how that information will be utilized. A consistent NCAA implementation policy including the type of test to be used and coverage of testing costs could improve implementation, results, and general satisfaction with the implementation of the screening policy. This may assist with separating issues related to the implementation of the screening from further overall discussion of the value of the screening policy itself.

IMPLICATIONS

A broader study of NCAA institutions in the United States will be useful in determining whether the knowledge, perspectives, and experiences of student-athletes and staff in DI schools in North Carolina reflect those of the national population. This information could enhance knowledge about the prevalence of SCT among NCAA student-athletes, which could have clinical, public health, and athletic implications.

REFERENCES

1. National Heart, Lung, and Blood Institute. Who Is at Risk for Sickle Cell Disease? http://www.nhlbi.nih.gov/health/health-topics/topics/sca/atrisk. Published September 28, 2012. Accessed June 12 2015.
2. Bonham, V. L., Dover, G. J., & Brody, L. C. (2010). Screening student athletes for sickle cell trait—a social and clinical experiment. *N Engl J Med, 363*(11), 997–999. https://doi.org/10.1056/NEJMp1007639.
3. Kark J. Sickle Cell Trait. http://sickle.bwh.harvard.edu/sickle_trait.html. Published December 20, 2000.
4. Mitchell, B. L. (2007). Sickle cell trait and sudden death—bringing it home. *J Natl Med Assoc, 99*(3), 300–305.
5. Rutkow, I. M., & Lipton, J. M. (1974). Some negative aspects of state health departments' policies related to screening for sickle cell anemia. *Am J Publ Health, 64*(3), 217–221.
6. Naik, R. P., Derebail, V. K., Grams, M. E., et al. (2014). Association of sickle cell trait with chronic kidney disease and albuminuria in African Americans. *JAMA, 312*(20), 2115–2125.
7. Thompson, A. A. (2013). Sickle cell trait testing and athletic participation: a solution in search of a problem? *ASH Educ Program Book, 2013*(1), 632–637. https://doi.org/10.1182/asheducation-2013.1.632.
8. Blinder, M., & Russel, S. (2014). Exertional sickling: questions and controversy. *Hematol Rep, 6*(5502), 66–70.
9. Eichner, E. R. (2011). Sickle cell considerations in athletes. *Clin Sports Med, 30*(3), 537–549. https://doi.org/10.1016/j.csm.2011.03.004.
10. Jung, A. P., Selmon, P. B., Lett, J. L., & Petrella, J. K. (2011). Survey of sickle cell trait screening in NCAA and NAIA institutions. *Phys Sportsmed, 39*(1), 158–165. https://doi.org/10.3810/psm.2011.02.1873.
11. Nelson, A., Deuster, P., Carter, R., III, Hill, O., Wolcott, V., & Kurina, L. (2016). Sickle cell trait, rhabdomyolysis, and mortality among U.S. army soldiers. *N Engl J Med, 375*(5), 435–442.
12. Markel H. Appendix 6. Scientific Advances and Social Risks: Historical Perspectives of Genetic Screening Programs for Sickle Cell Disease - Appendix 6.pdf. http://deepblue.lib.umich.edu/bitstream/handle/2027.42/85441/APPENDIX%206.pdf?sequence=1. Published n.d. Accessed February 5 2016.
13. Berman M. NCAA, Rice reach settlement with Lloyd family. http://www.myfoxhouston.com/dpp/sports/local/090628_lloyd_family_settl ement_rice. Published June 28, 2009.
14. National Collegiate Athletic Association. NCAA Football Rules Committee 2009–2010 Point of Emphasis. NCAA.org - The Official Site of the NCAA. http://www.ncaa.org/health-and-safety/medical-conditions/ncaa-football-rules-committee-2009-2010-point-emphasis. Published 2010.
15. National Collegiate Athletic Association. NCAA Division I Proposal No. 2009-75-B (as amended by Proposal No. 2009-75-B-1). http://www.hokiesports.com/sportsmed/resources/sickle-cell_FAQ_NCAA-div1-trait. Published 2010.
16. USDHHS Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. (2010). *Screening for U.S. College Athletes for Their Sickle Cell Disease Carrier Status*. http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/recommendations/correspondence/briefingcarrierstatus.pdf. Accessed March 3, 2015.
17. Stein R. Colleges Mandate Sickle Cell Testing. The Washington Post. http://www.washingtonpost.com/wp-dyn/content/article/2010/09/19/AR2010091904763.html. Published September 20, 2010.
18. Hendrickson B. DII Moves toward Start of Testing for Sickle Cell Trait. http://www.ncaa.org/about/resources/media-center/

news/dii-moves-toward-start-testing-sickle-cell-trait. Published January 30, 2012.

19. Brown G. DIII Approves Sickle Cell Measure. http://www.ncaa.org/about/resources/media-center/news/diii-approves-sickle-cell-measure. Published January 19, 2013.
20. Jones, J. D., & Kleiner, D. M. (1996). Awareness and identification of athletes with sickle cell disorders at historically black colleges and universities. *J Athl Train, 31*(3), 220–222.
21. Brown G. Sickle Cell Testing Proposal Referred in Division III. http://www.ncaa.org/about/resources/media-center/news/sickle-cell-testing-proposal-referred-division-iii. Published January 14, 2012.
22. Acharya, K., Benjamin, H. J., Clayton, E. W., & Ross, L. F. (2011). Attitudes and beliefs of sports medicine providers to sickle cell trait screening of student athletes. *Clin J Sport Med Off J Can Acad Sport Med, 21*(6), 480–485. https://doi.org/10.1097/JSM.0b013e31822e8634.
23. Chambers, H., Jr. (January 2008). *Civil Rights Act of 1964* (326–331). Encycl Supreme Court U S.
24. Koopmans, J., Cox, L. A., Benjamin, H., Clayton, E. W., & Ross, L. F. (2011). Sickle cell trait screening in athletes: pediatricians' attitudes and concerns. *Pediatrics, 128*(3), 477–483. https://doi.org/10.1542/peds.2011-0187.
25. Hensley S. Blood Doctors Call Foul on NCAA's Screening for Sickle Cell. NPR.org. http://www.npr.org/sections/health-shots/2012/01/26/145923225/blood-doctors-call-foul-on-ncaas-screening-for-sickle-cell. Published 2012. Accessed February 1 2016.
26. Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. Secretary's Advisory Committee on Heritable Disorders in Newborns and Children - Summary of the 21st Meeting - May 13–14, 2010, Washington, DC - minutes.pdf. http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/meetings/twentyfirst/minutes.pdf. Published 2010. Accessed February 1 2016.
27. Tarini, B. A., Brooks, M. A., & Bundy, D. G. (2012). A policy impact analysis of the mandatory NCAA sickle cell trait screening program. *Health Serv Res, 47*(1 Pt 2), 446–461. https://doi.org/10.1111/j.1475-6773.2011.01357.x.
28. Hartsell J. While Young Black Men Die, Debate Continues on Testing for Sickle Cell Trait. Post and Courier. http://www.postandcourier.com/article/20111023/PC1602/310239935. Published October 23, 2011. Accessed February 1 2016.
29. Office of Management and Budget. Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity the White House. Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity. https://www.whitehouse.gov/omb/fedreg_1997standards. Published October 30, 1997. Accessed April 14 2016.
30. McDonald, M. A., Creary, M. S., Powell, J., Daley, L.-A., Baker, C., & Royal, C. D. M. (2017). Perspectives and practices of athletic trainers and team physicians implementing the 2010 NCAA sickle cell trait screening policy. *J Genet Counsel, 26*(6), 1292–1300. https://doi.org/10.1007/s10897-017-0107-6.
31. Lawrence, R., & Shah, G. (2014). Athletes' perceptions of National Collegiate Athletic Association-mandated sickle cell trait screening: insight for academic institutions and college health professionals. *J Am Coll Health, 62*(5), 343–350.
32. Jordan, L. B., Smith-Whitley, K., Treadwell, M. J., Telfair, J., Grant, A. M., & Ohene-Frempong, K. (2011). Screening U.S. college athletes for their sickle cell disease carrier status. *Am J Prev Med, 41*(6 Suppl 4), S406–S412. https://doi.org/10.1016/j.amepre.2011.09.014.
33. Anderson, S. A., Doperak, J., & Chimes, G. P. (2011). Recommendations for routine sickle cell trait screening for NCAA division I athletes. *PM&R, 3*(2), 168–174.
34. The Sickle Cell Disease Association of America. Sickle Cell Trait and Athletics: Executive Summary. http://www.sicklecelldisease.org/index.cfm?page=sickle-cell-trait-athletics. Accessed July 20 2015.
35. American Society of Hematology. Statement on Screening for Sickle Cell Trait and Athletic Participation. http://www.hematology.org/Advocacy/Statements/2650.aspx. Published January 26, 2012. Accessed July 29 2015.
36. Centers for Disease Control and Prevention. Sickle Cell Trait Toolkit. http://www.cdc.gov/ncbddd/sicklecell/toolkit.html. Published August 26, 2015. Accessed 5 October 2015.
37. National Collegiate Athletic Association. (2010). *2010–11 NCAA® Division I Manual*. Indianapolis, Indiana.