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ORIGINAL RESEARCH

Perspectives and Practices of Athletic Trainers and Team Physicians Implementing the 2010 NCAA Sickle Cell Trait Screening Policy

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Abstract Sickle cell trait (SCT) is usually benign. However, there are some conditions that may lead to SCT-related problems and put athletes with the trait at particular risk. In 2010 the National Collegiate Athletic Association (NCAA) issued a policy that required all Division I (DI) student-athletes to confirm their SCT status or sign a liability waiver to opt out of testing. Athletic trainers and team physicians play key roles in the policy implementation and we examined their perceptions and practices. Between December 2013 and March 2014 we interviewed 13 head athletic trainers and team physicians at NCAA Division I colleges and universities in North Carolina. We used an interview guide with open-ended questions covering knowledge of SCT, historical screening and education practices, current implementation, and policy benefits and challenges. Participants were knowledgeable about SCT and thought the policy was beneficial in providing SCT health information to and for student-athletes. Schools varied in provision of genetic counseling, offering the waiver, SCT tests administered, and other aspects. Challenges included: insufficient guidance from the NCAA; financial considerations; and misunderstanding of the relationships of race and ancestry to SCT risk. Athletic staff found the policy valuable, but felt it needs clarity and standardization.

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Introduction

In 2010 the National Collegiate Athletic Association (NCAA) proposed a sickle cell trait (SCT) screening policy in the wake of the response and lawsuit that followed the death of an African American student-athlete who had SCT. This policy, approved and implemented in 2010, required that all Division I (DI) student-athletes beginning their initial season of eligibility and all students trying out for a team confirm their SCT status by a) undergoing a sickle cell solubility test, b) showing proof of prior testing for the trait or, c) signing a liability waiver if the athlete chooses to opt out of testing. The current NCAA policy is one of the largest SCT screening programs implemented by a private entity in the United States, and has been controversial (Ojodu et al. 2014; Tarini et al. 2012). While pre-participation physical examinations are required of all NCAA student-athletes, and pre-participation baseline concussion assessments are recommended as best practice, SCT is the only specific condition for which the NCAA requires a screening test. (J. Parsons, NCAA, personal communication 2015).

SCT is characterized by the inheritance of one normal beta hemoglobin allele and one sickle beta hemoglobin allele (HbAS). SCT should not be confused with sickle cell anemia caused by the inheritance of two sickle hemoglobin alleles (HbSS), or other forms of sickle cell disease (SCD) that include the combination of the sickle allele and other abnormal hemoglobin alleles (e.g. HbSC or HbSβ-thal) (Tsaras et al. 2009). These conditions are detected by routine state newborn screening programs for early identification of those affected and in order to prevent life-threatening infections and other causes of childhood morbidity and mortality (Ojodu et al. 2014). Unlike SCD

though, SCT status is typically not reported to families when detected through newborn screening. SCD and SCT are most common among people with ancestors from Sub-Saharan Africa, the Mediterranean basin, India, the Arabian Peninsula, the Caribbean, and South and Central America (The Sickle Cell Disease Association of America 2015a). In the United States, approximately 3 million people carry SCT, and it occurs in about 8% of blacks, .5% of Hispanics, and .2% of whites (Bonham et al. 2010; Kark et al. 1987; The Sickle Cell Disease Association of America 2015a).

SCT was once thought to be a benign condition; however, there is enough clinical evidence to suggest otherwise (Baskurt & Meiselman 2007; Grant et al. 2011; Jung et al. 2011; Ojodu et al. 2014; Tsaras et al. 2009). Complications that have been associated with SCT are well documented (Caughey et al. 2014; Folsom et al. 2015; Kark et al. 1987; Key & Derebail 2010; Tsaras et al. 2009). Studies examining the relationship between SCT and varying intensities of physical exertion, altitude, and heat have shown that complications associated with SCT can result in rhabdomyolysis, splenic infarction, pulmonary embolism, and hyphema (hemorrhage of the eye), among other non-traumatic injuries (Drehner et al. 1999; Gardner & Kark 1994; Kark 2000; Mitchell 2007). While linkages have been made with these complications, causation has not been established (Aloe et al. 2011; Blinder & Russel 2014; Ferrari et al. 2015).

The conditions that may lead to SCT-related problems—physical exertion, heat, and altitude—put athletes at particular risk. From 2000 to 2010, ten deaths were attributed to complications of exertional sickling among football players while conditioning (Eichner 2011). In 2011, Eichner estimated that approximately 3% to 4% of all DI football players carry SCT, yet 63% of all deaths in DI football during 2000–2010 were attributed to SCT. A study by Harmon et al. (2012) illustrated that NCAA football players with SCT have an exceptionally high risk of exertional death (1:827), 37 times higher than those without the trait. Yet prior to 2009, some screening for SCT was conducted at only half of the schools within the NCAA (Eichner 2010). In addition to the exercise-related complications associated with SCT, positive screening results have important reproductive implications and should be discussed with a genetic counselor.

In 2010, North Carolina Agricultural and Technical State University came under fire when a student-athlete recruit died during track tryouts. Prior to death, the athlete did not have a physical, a test to determine sickle cell trait status, or an NCAA waiver for SCT testing: clearly a failure to implement the policy (Witt 2010). As this tragic story shows, even though the NCAA instituted the policy in 2010, some schools were not in compliance. To date, implementation processes for the NCAA policy have not been extensively studied. Researchers have surveyed sports medicine providers, pediatricians, and college athletes about their attitudes, concerns, and perceptions of the policy prior to its implementation (Acharya et al. 2011; Koopmans et al. 2011; Lawrence & Shah 2014); however, there is no published study on the implementation of the policy from the perspective of those responsible for its implementation. All three divisions of the NCAA have now adopted the SCT screening policy (Brown 2013; Hendrickson 2012; Stein 2010). Given the significance of this policy for student-athletes with SCT and the fact that Division I was the first to adopt it, we sought to gather information from DI institutions in North Carolina, a state considered a hotbed of college sports, about their implementation of the 2010 policy. Head athletic trainers and team physicians play key roles in implementation. This paper examines their perceptions and practices approximately three years after the policy took effect.

Methods

We conducted telephone interviews to assess the knowledge, perceptions, and practices of head athletic trainers and team physicians at NCAA DI colleges and universities in North Carolina. We created a semi-structured interview guide designed to collect information on: knowledge of SCT, historical screening and education practices, current implementation practices, and perceptions of the benefits and challenges of the policy. We piloted the draft guide with an assistant athletic director.

Participant Selection and Recruitment

Athletic staff at Duke University and project consultants recommended that we focus on head athletic trainers, since they are primarily responsible for directing the implementation of the policy, and on team physicians, as they deal with health issues related to SCT. We contacted via email athletic directors at the 18 NCAA DI colleges and universities in North Carolina, via email, to ascertain their interest in their school's participation in the study. From those who expressed interest we requested the contact information for head athletic trainers and team physicians at their schools who were knowledgeable about the policy and spent time with student-athletes. We conducted 13 interviews by telephone between December 2013 and March 2014. Each participant received a $25 gift card.

Data Collection and Analysis Procedures

We digitally recorded each telephone interview with the participant's oral consent. Interviews lasted between 15 and 30 min. We labeled transcripts with code numbers to preserve participant confidentiality. Interview recordings were transcribed verbatim and then analyzed using NVivo 10 (*NVivo qualitative data analysis software; QSR International Pty Ltd. Version 10*, 2012), a qualitative analysis software program. Basic coding structure reflected a priori themes in the interview guide (Bernard & Ryan 2010). We wrote definitions for the codes and created additional codes for emergent themes as we analyzed the interviews in 2014–2015 (MacQueen et al.

1998; Miles et al. 2013). We discussed any differences in code assignment until we reached consensus. After coding the transcripts, we reviewed the data at each code to determine if they were covered by the code definition. We used a thematic analysis approach; examining the commonalities and differences within the data as well as relationships among data categories (MacQueen et al. 1998). We identified representative views of the respondents as well as outliers, allowing us to more accurately characterize the range of respondents' experiences and observations. All study procedures were reviewed and approved by the Institutional Review Board at Duke University.

Results

Characteristics of the Sample

We invited all 18 NCAA DI colleges and universities in North Carolina to participate in the study. Ten schools granted us interviews and three of those schools had two participants each, for a total of 13 interviews. Table 1 shows the characteristics of the respondents. Of the 13 participants, three were team physicians and the remainder were head athletic trainers. The sex breakdown was ten males and three females. Ages ranged from 31 to 63, with the average age being 43 years. Athletic staff members had been in their current positions from 1.5 to 30 years. Five were in their position for less than five years; five were in their position for over 10 years.

Topics and Themes

Current Knowledge and Historical Practices

One of the aims of the study was to assess the athletic trainers' and team physicians' current knowledge of SCT and SCD, including their awareness of the populations at risk and the potential consequences of carrying SCT. We asked the following questions: What causes sickle cell trait? What populations are at risk for having sickle cell trait? What may happen to people who have sickle cell trait? All of the 13 staff interviewed responded. One participant did not demonstrate any knowledge; 7 knew most of the information; and 5 knew that SCT was genetic, that having SCT was different from having SCD, that populations without African ancestry could carry SCT; and that people may not know they have SCT unless they have been tested. One athletic trainer explained:

> Obviously, it's an inherited trait. But you don't have the disease [SCD] but you have at least one gene for it. The athletes can have a nice full career without any problems, but you just have to be aware of it. Most people are obviously tested at birth, but we don't know that test and that's why we're doing all this stuff with the NCAA. But usually a lot of people don't know they have it because they actually do fine with it.

Like this respondent, others alluded to newborn screening at various points during the interviews. However, as one might expect, there was a lack of awareness among some respondents about the availability of newborn screening results for SCT. Many assumed families already knew those results. For example, an athletic trainer asked, "…if you're 17, 18 years old you've already been competing at a high level, you've played DI athletics. How could you not know what your screening [status] is?"

We also observed that a few respondents repeatedly used the term "sickle cell athlete" to refer to a student-athlete with SCT. Individuals may have been using this as short hand for "a student-athlete with sickle cell trait", and may be unaware that the term is both misleading and potentially stigmatizing.

With regard to previous screening for SCT, 10 of the 13 respondents reported that their institutions did not screen athletes for SCT before implementation of the policy, and that SCT did not receive any attention from the athletic staff. Two respondents indicated their schools had been screening some athletes since 2008. One of these respondents described the screening as follows:

> Screening at that time [before the 2010 policy] was voluntary. Obviously it was part of our pre-participation screening process, part of the physical exam, especially for those student-athletes more than likely that would have the sickle cell trait. We did not require official sickle cell [trait] testing.

Opting Out

When creating the 2010 policy, the NCAA DI Legislative Council offered a waiver in response to some NCAA

Table 1 Characteristics of Participants ($N = 13$)

	N or Mean ± SD	% or (95% CI)
Sex		
Female	3	23.1%
Male	10	76.9%
Age (Years)	43.8 ± 8.8	(38.5, 49.1)
Job Title		
Head Athletic Trainer	10	76.9%
Team Physician	3	23.1%
Race[a]		
Black	2	15.4%
White	11	84.6%

[a] As defined by 2010 U.S. OMB categories

conferences that requested it (Bonham et al. 2010; Quick 2011). Of the 10 schools in our study, 3 allowed a waiver and 6 did not. Responses from the 10th school were inconsistent: the athletic trainer reported their school did not offer waivers and the team physician stated they were provided. One of the respondents who said that his school did not offer the waiver explained, "We did that [made waiver available] for a year and then we moved [our stance]. It was really legal [the legal department] who indicated they would prefer everyone to be screened."

Of the 3 schools that did allow a waiver, one did not participate in football. Another school allowed the waiver only for religious reasons. A staff member from this school reported that despite offering the waiver, they captured the majority of athletes: "Let me just say that 99% of the time our student-athletes will get blood drawn. I can't say in the last four years we had absolutely 100%, but I know that for the most part they have all, 99% have, complied." A head athletic trainer said he did not have a problem offering the waiver, but that many of the athletes "just go ahead and do it [get screened]." When asked for their specific reasoning behind the allowance of waivers, he replied, "Some of them will [say], 'Hey, I'm white, I don't think I have it. I don't like needles."

Race and Geographic Ancestry

While we did ask about the "race" of our respondents and whether all athletes are screened (i.e. implementation of the waiver), we did not ask directly about the racial classifications of the athletes or how race may play a role in perceptions around screening. Despite this, themes around race- or ancestry-based risk associations emerged. When we asked questions about general knowledge of SCT, many respondents replied with answers that linked the sickle allele to African ancestry and the diasporic population of blacks in America. Some respondents also spoke specifically about geographic regions where they thought there was a low risk of SCT being present in the population.

In response to our question about the challenges of the policy, an athletic trainer mentioned that a coach at his school, who recruits student-athletes from certain geographic regions, gives substantial pushback concerning the policy:

> One in particular, he recruits primarily eastern European females who are at the lowest risk category as possible and he doesn't understand why we're requiring this when they're not at risk. He is not grasping that they are at risk; it's just very, very unlikely.

After asking a team physician about his university's policy on opting out, he referred us to the head athletic trainer, but responded, "If they can opt out I don't have a problem with that. Some Scandinavian kid, the risk is a little on the low side shall we say."

Benefits and Challenges of the Policy

Eight out of ten respondents indicated that the SCT screening had benefits. The most common benefit mentioned was that the knowledge of who had SCT enabled athletes to be aware of the condition in themselves and in others, and helped staff take steps to prevent potentially serious problems. A director of athletic training described benefits as, "More knowledge to try to prevent tragic incidents. It's another tool for us to try to prevent something from happening. It's also been educational for all involved, about the risk of sickle cell trait." An athletic trainer said, "I also have found student-athletes who didn't realize they were sickle cell [trait] positive, therefore I do think there is certainly a positive merit to that [testing]."

In providing his perspectives on the benefits of the screening policy, one athletic trainer weighed the benefit of knowing an athlete's trait status against the cost of testing. His comment was framed around race or ancestry:

> I think it's very reassuring to know who is or who is not [positive for SCT]. I think that's been fabulous, that we have absolute certainty of who is or who is not [positive for SCT] and the medical staff knows that and the coaching staff knows that as well, and that's been great. The policy, we know there's obviously a higher yield of those who have sickle cell trait based upon their demographic. But it is quite honestly, we have such a small number of student-athletes that have sickle cell [trait] that it is a tremendous expense.

When we asked respondents specifically about challenges, two reported none. Other participants cited many challenges such as, insufficient information from the NCAA on how to implement the policy, financial burden of test costs (especially among the smaller schools), and some athletes not adhering to training regimens. The most commonly reported challenge was not getting the test results in time to clear athletes for practice.

Much confusion emerged around the perceived lack of direction from the NCAA. A director of athletic training stated: "It's not necessarily a mandatory screening because the athletes were allowed to sign a waiver and waive out of it. So the term *mandatory* was very confusing to people." In addition, other respondents mentioned the lack of specific information about how certain aspects of the policy should be executed, such as the test required to screen for SCT. An athletic trainer expressed this as follows:

> NCAA is very vague about what they require; they just say that it's required. Because there's a lot of different tests, there's no specific as to what test is required or

> what numbers you have to have or what the results have to say. It's just you have to be tested and you have to have results.

Questions about the reasons behind the implementation of the policy posed a challenge for some. Four respondents expressed concern that the policy was primarily a reaction to the 2008 lawsuit brought against the NCAA, and dismissed the idea that the policy resulted from a genuine interest in the health of student-athletes. A team physician stated, "I thought it was completely ridiculous and all driven by [the] legal [department] and not medical, quite frankly." Others wondered about the lack of testing for other potentially dangerous medical conditions, such as heart problems.

Some respondents were concerned that athletes did not understand the implications of having SCT. An athletic trainer reported:

> The only challenge is some student-athletes who never had a problem, when you tell them they have sickle cell [trait] and try to hold them to the training regimen they feel like they don't have a problem, there's nothing wrong with them, but they've got to–why they've got to do the different regimen or why their regimen is altered. They feel like nothing's wrong with them because they really don't understand.

This quote from an athletic trainer aptly summarizes the sentiments of multiple respondents regarding challenges of the policy:

> So while I think it's a good idea on one side, obviously it's [SCT status] important information. The other side is just how we implement the testing, importance, and how soon can we start athletics, and why does everybody have to have it, what are the financial considerations. All those, certainly I don't think were well thought out, in my opinion, before we instituted this. So I think that was some of the frustration with myself [for me] and many of my colleagues, is how you would implement this.

Discussion

Although some research has addressed the NCAA SCT screening policy itself (Grant et al. 2011; Jordan et al. 2011; Tarini et al. 2012; Thompson 2013), to our knowledge this is the first published study to provide data obtained directly from athletic staff with experience (3 years) implementing the policy. This study sheds light on staff perspectives and how the policy might/may be executed at some DI colleges and universities. It presents evidence for several of the ethical, societal, scientific, and practical considerations that other authors predicted (Bonham et al. 2010; Grant et al. 2011; Jordan et al. 2011; Thompson 2013), and will be useful to schools and to the NCAA as they seek to enhance the benefits of the screening program and address areas of concern.

The NCAA and some of the institutional athletic departments provided their athletic staff with educational materials on SCT, and we found that almost all of our study participants were knowledgeable. It is unknown where this knowledge comes from and how consistent it is across schools. Institutions may have different SCT education standards since the NCAA does not require that student-athletes, coaches, and trainers access any resource as part of the screening process (Ferrari et al. 2015). In addition, the educational material available from the NCAA addresses the athletic impact of SCT; it does not address the broader health and reproductive consequences that a positive SCT screening result may have for both the student-athlete and their family members (Bonham et al. 2010; Natowicz & Alper 1991). Athletic staff reported that they, along with student-athletes, appreciated the increased SCT knowledge. Some respondents assumed, however, that parents, and thus student-athletes, would be aware of their SCT status by the time they participate in DI sports programs. State newborn screening programs test babies at birth for SCD, and through this process also identify babies with SCT, meaning they carry a hemoglobin S allele that they could pass on to a child (Lane 2001; National Institutes of Health 2016). Although every child in the US is presumably tested at birth, most newborn screening programs are required to report only SCD, not trait status. Additionally, newborn screening data are incomplete and reporting procedures vary from state to state (Ojodu et al. 2014). Due to the assumed benign nature of SCT in clinical and public health discourse, many physicians who do relay trait information to parents also often downplay the potential consequences of the trait. Comprehensive education about SCT (and SCD) should include information about accurate and non-stigmatizing terminology to describe people with these conditions. For example, the term" sickler" has historically been used in medical discourse to describe individuals living with sickle cell disease. Members of this patient population have voiced discomfort with this label and may view it as a sign of disrespect (Bediako et al. 2016; Wailoo 2006). As a general best practice, individuals should be trained to avoid the attachment of medical characteristics to individuals.

Across the schools, the use of the waiver was inconsistent and confusing. It appeared some schools and athletes were using the waiver generously and frequently based on the perception that only certain people were at risk of having SCT, therefore it was unnecessary to test all student-athletes. The NCAA SCT screening is designed to capture every student-athlete that participates in a DI (and now DII and DIII) sport; however, because many people mistakenly think SCT only affects those with African heritage, the waiver potentially

facilitates singling out and labeling black athletes as the only ones for whom the policy was designed (Naik & Haywood 2015). None of the participants mentioned instances of stigmatization or discrimination; however, many did mention their frustration when the screening policy delayed the start of training. This frustration was especially apparent when student-athletes were thought to have low risk for the presence of an S allele, yet could not practice until their test results came in. There is certainly the potential for this frustration to lead to lapses in compliance with the policy, whereby black student-athletes are targeted and others easily allowed to opt out: thus reinforcing stigma attached to blackness (Jenerette & Brewer, 2010; Wailoo 2006). Black student-athletes already potentially face longstanding challenges such as racism and racial stereotyping on predominantly white campuses (Njororai 2012). Additional research is needed to determine whether the required screening fosters stigmatization and discrimination, or increased knowledge and impartial attitudes about race- or ancestry-based risk.

Practice Implications

Along with noting personal, practical, and educational benefits to both athletes and the staff themselves, study participants identified several challenges related to the policy. A common theme regarding challenges was the perception that the NCAA's lack of guidance left them unclear about the best procedures for fulfilling the policy. As a result, staff employed inconsistent practices across athletic programs. For example, due to variation in the costs of tests for SCT status, schools used different tests based on their budgets. Perhaps related to test cost and lack of guidance from the NCAA, respondents from only two of the 10 participating schools, mentioned that genetic counseling was provided for students who tested positive. In their sports medicine handbook, the NCAA states that if a student-athlete tests positive for SCT, he or she "should be offered counseling on the implications of sickle cell trait, including health, athletics participation and family planning (National Collegiate Athletic Association 2014)." There is no clarification, though, on who should provide this counseling or how the costs should be covered, and it is evident from our data that the counseling may not occur at all schools. Thus, student-athletes may not be receiving adequate information regarding the risks and benefits of testing in order to make an informed decision to participate in testing (Ferrari et al. 2015). Determining an athlete's trait status is not sufficient to protect them from potential harm; the athlete must also understand why screening is being done, and what the results could mean. There are important implications of a positive SCT test, and they extend beyond training and the athletic field (Ferrari et al. 2015; Jordan et al. 2011). The solubility test, which many schools use, only tests for hemoglobin S and may not identify other variants, including thalassemia, which can be passed to offspring. Those receiving positive SCT test results should be provided with emotional support and explanations of genetic information specific to an individual's needs, interests, and circumstances. The NCAA screening may be the first time student-athletes encounter genetic testing, therefore comprehensive genetic counseling practices are recommended (Ferrari et al. 2015). Ferrari et al. (2015) and others suggest that an "opt in" program by the NCAA, instead of the current policy with the "opt out with waiver" option, could address some of the policy's gaps and inconsistencies by following consistent, required SCT education and offering counseling to all student-athletes identified with SCT. This approach might also better respect student-athletes' autonomy and protect their privacy (Ferrari et al. 2015). In addition, organizations such as The American Society of Hematology, Sickle Cell Disease Association of America, and American College of Sports Medicine have all advocated for genetic counseling for each individual who receives a positive screening result to communicate information not only about possible health risks, but also reproductive risks (American Society of Hematology 2012; The Sickle Cell Disease Association of America 2015b; Thompson 2013). Some schools are incorporating genetic counseling into their screening program and can serve as models for other schools (Ferrari et al. 2015). Genetic counselors are essential because they can provide accurate and appropriate information directly to student-athletes and serve as resources for staff. Student-athletes should be informed about possible results and their implications, SCT symptoms and implications for health, NCAA-recommended precautions related to athletic and physical exertion, and reproductive and familial significance of SCT (passing on an abnormal allele to a child, reproducing with another SCT carrier thus increasing the chances for the child to have SCD) (Ferrari et al. 2015).

This study reveals ethical issues around screening that have yet to be resolved. If screening is mandatory, issues such as autonomy, beneficence and privacy need to be carefully considered and addressed for this policy to be ethically appropriate (Aloe et al. 2011). The existing program raises concerns about the autonomy of student-athletes' decision-making and the schools' ability to satisfy the requirements of informed consent for medical testing without appropriate genetic counseling (Ferrari et al. 2015). The CDC has recommended that SCT screening programs have policies to protect an individual's privacy (Grant et al. 2011). This is critical to respect the person and the privacy of health information, and to help protect student-athletes from stigma and discrimination.

This study revealed potential tensions between athletic staff who had no buy-in to the 2010 policy and believe they lack resources and clear directives, and a governing body perceived to be reacting to a lawsuit. As an alternative to a testing policy some branches of the military have used a system

called universal precautions; a protocol of supervision and actions designed to prevent exertional heat illness (EHI) for everyone in the group exercising. This includes: hourly monitoring of the ambient temperature; decreasing exercise intensity and increasing rest time when temperature reaches 90 ° F; increasing and monitoring water intake; wearing light-weight clothing; and beginning cooling and rehydration and monitoring body temperature at the first sign of heat distress (Kark et al. 2010). The use of universal precautions has had some success with military recruits (Gardner & Kark 1994; Kark et al. 1987); however, this system has not eliminated deaths to which SCT may have been a contributing factor (Ferster & Eichner, 2012). Despite the tensions and remaining questions, each staff member we interviewed valued having SCT health information for student-athletes.

Study Limitations

A limitation of our study is the small sample size. At seven of the ten participating schools we interviewed only one member of the athletic staff, so we may not have received complete information about how they implemented the policy. At the schools where we interviewed two staff members, we were able to get a more comprehensive view of implementation practices. We interviewed head athletic trainers and team physicians because these staff were most closely involved with implementation related to the policy; however, this limited our data to the views of these two staff positions. Qualitative research uses the concept of "saturation" meaning that data gathering is not yielding any new information. Data saturation indicates that enough people have been interviewed on that topic (Guest et al. 2006). Due to the small sample size, some topics were near saturation of information and others were not. Topics on which we did not gather enough data we either did not include in this paper or, if included, we indicated that only a few participants discussed them.

Secondly, our data may not be generalizable, since they are only from North Carolina, and implementation of the policy may differ in other states. Thirdly, it was challenging to conduct full-length interviews, given time constraints resulting from the competing demands of the participants' athletic duties. We arranged all interview appointments in advance; however, participants would often indicate at the beginning of the interview that they only had a few minutes, and were often traveling. Due to the topic and specific interview questions, a few participants seemed defensive about the questions and this constrained some of their responses.

Conclusions

Despite its limitations, our research uncovered a variety of issues that need to be addressed to facilitate: 1) the identification and safety of all NCAA student-athletes with SCT; 2) adequate preparation of athletic staff to effectively implement the NCAA SCT screening policy; and 3) equitable distribution of resources and infrastructure for schools to support the policy. Further research is needed to determine the extent to which the findings from DI schools in North Carolina reflect perspectives and experiences nationally.

Research Recommendations

Directions for future research include investigations of regional differences (e.g., higher versus lower altitude states), differences between NCAA conferences or divisions, and differences between types of schools (e.g., Historically Black Colleges and Universities versus other schools) in terms of practices (e.g. availability of genetic counseling, educational materials, waiver use, and the type of SCT tests used) and the views of a range of key stakeholders including student-athletes with and without SCT. It is critical to develop a more complete picture of how the NCAA SCT screening policy affects schools, staff, and student-athletes in order to maximize its benefit and minimize its harm.

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Compliance with Ethical Standards

Conflict of Interest Author McDonald, Author Creary, Author Powell, Author Daley, Author Baker, and Author Royal declare that they have no conflicts of interest.

Human Studies and Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained orally from all participants in the study.

Animal Studies No animal studies were carried out by the authors for this article.

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