

A New Tuskegee Experiment?

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BY

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In a situation with unsettling similarities to the infamous "Tuskegee Study of Untreated Syphilis in the Negro Male," youth and college football players today are part of what amounts to a massive and unethical experiment in concussions. The Tuskegee Study violated basic bioethical principles of respect for autonomy (participants were not fully informed in order to make autonomous decisions), nonmaleficence (participants were harmed, because treatment was withheld after it became the treatment of choice), and justice (only African Americans were recruited). As at Tuskegee, the concussion experiment violates basic bioethical principles. Until the pathological processes of concussions are understood and methods of prevention are tested, there should be major changes in the game of football to decrease, if not eliminate, this primary cause of head trauma in young men.

The football concussion experiment differs from the Tuskegee Study in a key way, namely, concussion investigators are not knowingly misleading subjects to participate as was done at Tuskegee. Indeed, what makes the comparison so illuminating is that coaches, parents, and health professionals all have the best interests of youth at heart. Nevertheless, efforts are only recently under way to define the level of risk, refine the diagnostic techniques, and explore effective treatment for head injuries, all while it is well-known that the forceful collisions that are intrinsic to tackle football place hundreds of thousands of youth and young men at risk of harm from acute and chronic neurological damage. Furthermore, according to data from the National Collegiate Athletic Association, in 2009-10, for the first time, the percentage of African-American males composed the largest segment of football players (45.8 percent), greatly exceeding the percentage in the U.S. population (slightly less than 13 percent). This means that African-American football players face a disproportionate exposure to the risk of concussions and their consequences.

Using data from 100 high schools in the High School Sports-Related Injury Surveillance Study, Marar, et al. reported rates of 3.1 per 10,000 athletic exposures for boys, reflecting 1,432 concussions. Football had the highest risk of concussion (6.4 per 10,000 athletic exposures (a unique game or practice), followed by boys' ice hockey at 5.4), but due to the much wider participation in football, that sport accounted for 64 percent of the concussions in boys. In a previous study from the same data base, Gessel et al. calculated that the 201 reported football-related concussions in 2005-6 projected to a national estimate of 55,000 concussions. The NCAA Injury Surveillance System reported 245 football-related concussions. Although a national estimate comparable to the high school estimate was not available, football accounted for 70 percent of the collegiate concussions among males.

Medical and legal concern over the acute treatment and long term consequences of these injuries has prompted many responses. In 2010, the American Academy of Pediatrics noted, "The long-term effects of concussions in athletes of all ages are cause for considerable concern. With a lack of long-term prospective studies in high school and younger athletes who sustained concussions, there are more questions than conclusive answers." The Consensus Statement on Concussion in Sport recommended, "a more conservative return to play approach for children and adolescents,"

motivated, it seems, by the lack of a sufficient evidence to offer more nuanced advice. Indeed, the statement notes that "concussion is considered to be among the most complex injuries in sports medicine to diagnose, assess, and manage. The majority of concussions in sport occur without loss of consciousness or frank neurologic signs. At present, there is no perfect diagnostic test or marker..."

The devastating cases of early dementia, depression, and suicide among former professional football players serve as sentinel indicators in football. The epidemiological evidence linking concussions to these outcomes is growing and has prompted the expenditure of tens of millions of new federal and private research dollars, as well as public education campaigns by the Centers for Disease Control and Prevention and the NCAA. As critical as these research and educational efforts are, it is important to point out that the resources are directed, for the most part, at attempts to ameliorate the trauma after damage has already occurred. More precise neurological scans and more sophisticated biochemical tests do nothing to reduce the incidence of concussions. While there is a risk of concussion in most sports, football is unique in two ways. First, the over 4 million youth and high school players and over 65,000 college players, dwarfing other sports where concussions can also occur, mean that football contributes disproportionately to the concussion problem. Second, even with increasingly expensive equipment, the human body in general and the brain in particular are not designed to withstand the repeated high-energy collisions inherent to the sport as it is currently played.

Research on the risk of concussions should proceed only in carefully controlled, clinical trials, guided by the ethical principles that pertain to any medical or public health study. Until the risks are sorted out, only adults who have the autonomy to consent to participation in research should be exposed to tackle football, largely the professionals whose generous compensation enters into their personal calculations of risk and reward. In violation of the principle of autonomy, are parents of children and young college players themselves fully informed of the risks? Do non-professional players who have reached the age of consent sign agreements that meet the rigorous standards of medical research? Given that the medical community simply does not know the extent of the harm that can result from even one concussion, not to mention the fact that damage results even when there are not sufficient symptoms to diagnose concussion, continuing to allow the literally uncontrolled participation in football violates the harm principle, even if there were adequate consent.

A ban on youth and high school football, so deeply entrenched in U.S. culture, does not seem feasible. In order to reduce harm, however, there could be immediate changes in the rules. For example, restrict participation to those above a certain age, use flags instead of tackling, and change the blocking rules. When it comes to college, players are old enough to consent formally. However, the fact that only a tiny percentage go on to play professional football and earn fabulous salaries means that the benefits may not justify the risks. To meet our ethical obligations given that the potential harm is so great, it is only through a formal clinical trial type research process that college football should proceed.

Finally, not only does the disproportionate participation of African-American males in football unfairly expose them to yet another risk of poor health, but also raises the question of whether African-American communities have the information they need and deserve to consider and

consent to this risk for their sons. Out of fairness, special attention should be paid to these ethical principles in African-American communities, whose boys and young men, sadly, experience increased risks of poor health for many reasons other than football.

The Tuskegee Study was a tragedy, but its lessons about racism and unethical research have strengthened research endeavors. In issuing a formal apology in 1997, President Clinton mentioned an important public health ethical principle: That communities should be provided with the information needed to decide on participation in studies and should have a mechanism to provide community consent.

Participants in football should be afforded the same treatment. Football-related head trauma and concussions have raised sentinel alarms, so all who care about children and young adults must not remain silent as this epidemic spreads. The principles of informed consent, nonmaleficence, fairness, and community participation demand a halt in the way the game is played, until the risks are better understood and controlled.

BIO

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