CTE: Is The Media Scaring Young Athletes To Death?

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As someone who has been educating sports parents about head trauma in sports for the past seventeen years, and about the very real risk posed by chronic traumatic encephalopathy (CTE) for the last decade, it is not surprising that I receive emails from parents all the time expressing deep concern about stories in the media that have led them – wrongly – to fear that playing contact or collision sports, or suffering a sports-related concussion, especially one slow to heal, makes it inevitable that their child will develop CTE and is at greatly increased risk of committing suicide.

When a recent email prompted me to pick up the phone to talk to one concerned mother, she told me that her son – who had suffered a concussion playing indoor lacrosse, but, seven months later, and after seeing a number of concussion specialists, was still experiencing symptoms – was giving up hope of ever getting better. Most disturbingly, she said he had begun expressing the belief that he might be better off dead, because at least then he would no longer be a burden to his family and community and, if his brain ended up in a jar next to those of other athletes who also had CTE, perhaps he might find a place in medical history.

My reaction was one of sadness, frustration, and worry: sadness that a young athlete simply assumed that he had CTE as a result of a single concussion and considered it to be a death sentence; frustration that, despite concerted efforts by researchers and clinicians, along with some in the media, to set the record straight on CTE, the prevailing media narrative continues to be that concussions or repetitive subconcussive blows “cause” chronic traumatic encephalopathy (CTE), that CTE “causes” former athletes to commit suicide, and that such causal links are proven scientific fact (they’re not); and, finally, worry: concern about the consequences of the football=CTE and CTE=suicide memes in the real world.

For the authors of a 2016 editorial in the *British Journal of Sports Medicine* the tragic case of a former NHL player, Todd Ewen, is Exhibit A of those real-world consequences. Suffering from bouts of depression – which he was convinced were the result of CTE – and terrified at the thought of a future living with an untreatable neurodegenerative disease, Ewen committed suicide at age 49. But before an autopsy could even be performed, the media’s verdict was in: his depression and suicide were most likely the result of a career in the NHL, repetitive head trauma, and the inevitable onset of CTE. A subsequent autopsy, however,
found no evidence of CTE.

How, asked the authors - three researchers at Vanderbilt and an epidemiologist at the University of North Carolina - Chapel Hill - did an athlete with treatable depression come to believe that he had an untreatable condition and commit suicide? Because, they asserted, the media, ably aided and abetted by Dr. Ann McKee of the Department of Veterans Affairs and Boston University's CTE Center, along with the PBS series, *Frontline*, had for years been using the results of autopsies of the brains of a small, self-selected group of former athletes to create a "sensationalized state of fear" about CTE.

To make matters worse, they argued that many in the media – most especially, in my personal experience, those active in social media – not only ignore and/or severely criticize research findings that don’t fit the football=CTE and CTE=suicide narrative, but label anyone who dares to challenge that narrative or call for further study a ‘CTE denier’ or a ‘shill’ trying to advance their own vested interests,* confuse the public and conflate the issues, or all the above.

Are cases like Ewen outliers or do they represent an increasingly common and worrisome phenomenon? Unfortunately, it appears to be the latter. Every clinician who routinely treat athletes with post-concussion syndrome (i.e. patients whose symptoms after suffering a sports-related concussion persist for months or years), with whom I spoke for this article expressed variations of the same concern: that their patients, hearing media reports about athletes suffering symptoms associated with CTE (such as depression), were losing hope of a full recovery, to the point of considering suicide.

“As a clinician, I see patients that come to our clinic months and years after they’ve been diagnosed with a concussion,” said Shannon Bauman, MD, director of the Concussion North Clinic in Barrie, Ontario, Canada. It is “very concerning,” she said, “when my patients share their story and fears that they will not recover, and are being told by physicians and other health care providers that they trust that they will likely not get better and that living with lingering symptoms was likely to be their ‘new normal.’ Without hope, patients begin to believe that they will not recover,” Bauman said. “For young athletes, this can be devastating. Without hope, they begin to believe the messaging from media focusing on professional athletes who have died and been found to have CTE. This takes a great toll on the mental health of a patient recovering from a prolonged concussion leading to increased anxiety and depression, and even thoughts of suicide.”

The problem, argues Bauman, is that too many media stories focus on professional athletes, CTE, and poor outcomes of prolonged concussion (or sports exposure to repetitive head
Likewise, in her practice, Elizabeth Pieroth, Ph.D., Associate Director of North Shore University Health System’s Sports Concussion Program, says she has seen a number of youth patients (athletes and non-athletes) who have sustained a concussion and believe they now have or are going to develop CTE. “On too many occasions, I have had young people crying in my office that they were going to ‘die of CTE,’ even after just one concussion.”

As heartbreaking as such encounters are, said Dr. Pieroth, she saw a silver lining: at least they afforded her the opportunity to educate them on the current state of the science on concussions and CTE. “What worries me,” said Dr. Pieroth, “are the countless people who have the same fear but are not being seen by healthcare professionals with the appropriate training and experience to adequately address this issue.”

The experience of Rosemarie Scolaro Moser, Ph.D, Director of the Concussion Center of New Jersey, was much the same. “In the past year, we’ve seen more young athletes at our Center who are overly anxious and worried about CTE,” she said. “This worry has become irrational to the point that they are afraid to engage in normal activities for fear of further brain damage, even when it is clear to us that they have recovered. It’s as if they have equated the diagnosis of concussion with doom and a sentence of irrevocable brain damage.” She pointed to one patient, a high school athlete, who had clearly recovered from his concussion – to the point that he was performing in the superior range on neuropsychological testing and getting As in school – who was nevertheless so worried,
anxious, and paranoid about hurting his head again that he thought he’d suffered another concussion when he happened to turn his head quickly from side to side! She wondered whether the media frenzy over CTE was creating a new medical condition she dubbed “Concussion Anxiety Syndrome.”

Like Dr. Pieroth, she said that it was the responsibility of concussion specialists to directly address the emotional component of concussions and undo the myths to which athletes and their parents have been exposed as result of the “media hype” about CTE. “It’s not always easy undoing the misinformation out there. Now, it is my job not only to help manage the concussion and facilitate recovery, but to challenge the myths and educate athletes and parents about the facts. We still do not have clear, medical, scientific data that indicates that concussion leads to CTE. We still don’t know enough about it. We do know that most concussions resolve, that we should expect concussions to resolve, and that there are plenty of athletes who have had multiple concussions who do not have the emotional disturbance, brain damage, and suicidality that may be portrayed in the media.

Media reports on the finding by Dr. McKee and her colleagues in a new study reported in the *Journal of the American Medical Association* that 110 of 111 deceased NFL players her group had autopsied had CTE will undoubtedly take the level of fear among sports parents and present and former athletes in all contact and collision sports alike to even more frenzied heights.

While I was encouraged by the amount of push-back from scientists, clinicians, and researchers objecting to the way in which the media has covered the story, and cautioning that the facts about CTE are far more nuanced and uncertain that many in the media would have us believe, I am concerned that their voices aren’t being heard. For every article by a scientist calling for an “end to the media and public hysteria,” and for both sides to “stop campaigning for their agenda and to let science take the lead,” there are one hundred, or even one thousand, which will do nothing more than repeat the scariest of the study’s findings: that 99% of those who played in the NFL whose brains were autopsied had CTE.

I worry that lost amidst the hoopla about the new CTE study is the fact that not every football player whose brain was donated to the CTE Center for pathological scrutiny was found to have the disease, and, that it was not detected in either the brains donated by the families of football players who died before they got to high school, and in only three of fourteen of high school players (and, in those, the disease had not progressed beyond the “mild” stage).

What I found most surprising was, that as far as *The New York Times* and Dr. McKee were concerned, her study didn’t add to the debate about the football=dementia narrative; it
ended it. According to the *Times* – which is widely acknowledged to have *originated* the football=CTE and CTE=suicide narrative in a January 18, 2007 article – all that was left for scientists to figure out was “how many blows to the head, and at what levels, must occur for C.T.E. to take hold.”

Not only was that assertion completely at odds with the uncertain state of the existing science, but it was contradicted by the study itself, in which Dr. McKee and her colleagues acknowledged that several other factors, besides prior participation in football, may influence CTE risk and disease severity, *including factors other than cumulative hits to the head*, and admitted that it was even “unclear” what roles concussions and repetitive subconcussive hits play in CTE risk, disease severity, and progression.

That the *Times* didn’t report these findings, much less bother to interview anyone for the article other than Dr. McKee, wasn’t at all surprising to me (and, I’m sure, to many scientists) for one simple reason: such uncertainty didn’t fit the *Times*’ 10-year football=CTE meme.

Educating sports parents and athletes about head injury safety is tough enough without the media’s sensationalist reporting, but it does come with its rewards. Recently, I received an email from a mother asking for help for her son, an ice hockey player, who was struggling with post-concussion syndrome to the point he was suicidal. I reached out to the clinicians on our organization’s Head Injury Advisory Board to see if anyone could help. One of our members responded immediately, and, working with the athlete and his family, has developed and implemented a treatment plan that is putting him on the road to recovery. I would like to think that I played a part, however small, in that positive outcome.

Now, if only the media could focus its energies on educating the public instead of sensationalizing head injuries in sports, perhaps we could stop creating such a climate of fear that athletes end up literally being scared to death.

Share your story with me at delench@MomsTEAM.com

* In the interest of full disclosure, neither I nor MomsTeam Institute, the non-profit of which I am the Founding Executive Director, has ever accepted any donations from the NFL, USA Football, Pop Warner, or any equipment manufacturer. In order to remain fully independent and objective, this has always been our policy.
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