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When Athletes Ask About Chronic Traumatic Encephalopathy

Shae Datta[1,2], Brian S. Im[2,3], Geraldine Pagnotta[2,3], Mara Sproul[2,3], Rebecca D. Folkerth[4], Enna Selmanovic[5,6,7] and Hector Arciniega[2,3,8*]

Abstract

Athletes exposed to repetitive head impacts (RHI) may seek clinical evaluation because of concerns about chronic traumatic encephalopathy (CTE), a neuropathologically defined disease that cannot currently be diagnosed during life. As public awareness of CTE has expanded, clinicians face challenges communicating diagnostic uncertainty, interpreting non-specific symptoms, and addressing concerns about future neurological health. This Current Opinion examines the widening gap between public expectations and scientific capability and considers its implications for athlete-centered care. We discuss how clinicians can acknowledge uncertainty without dismissing patients' concerns, identify potentially treatable contributors to symptoms without prematurely attributing them to neurodegenerative disease, and use shared decision-making to guide individualized evaluation and management. We also consider how concerns about CTE may influence decisions about continued participation and return-to-sport among current athletes. Meeting these challenges requires coordinated interdisciplinary care, evidence-based communication, and clinical approaches that prioritize meaningful intervention even when diagnostic certainty remains unavailable.

Key points

1. Chronic traumatic encephalopathy is neuropathologically defined and cannot currently be definitively diagnosed during life, creating challenges when athletes seek individualized explanations of symptoms or future neurological risk.
2. Clinical evaluation should prioritize identification and treatment of potentially modifiable contributors to symptoms while clearly communicating the limits of current CTE diagnostic and prognostic evidence.
3. Structured communication, shared decision-making, and interdisciplinary care can provide athletes with actionable guidance even when diagnostic certainty about CTE is not possible.

*Correspondence:
Hector Arciniega
hector.arciniega@nyulangone.org
Full list of author information is available at the end of the article

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Introduction

Former athletes with histories of repetitive head impacts (RHI) present to sports medicine, neurology, and concussion clinics asking a deceptively simple question: "*Do I have chronic traumatic encephalopathy (CTE)?*" Although the question is straightforward, the answer remains beyond the reach of contemporary clinical neuroscience. CTE has become one of the most publicly recognized neurodegenerative diseases despite remaining impossible to diagnose definitively during life [1–4]. In a recent study, approximately one-third of former professional American football players reported believing that they had CTE, illustrating how this neuropathologically defined condition has become part of how some athletes interpret their neurological and psychological health [5]. As public awareness has expanded, sports medicine physicians, neurologists, physiatrists, neuropsychologists, and concussion specialists increasingly find themselves navigating conversations in which patients seek certainty that current science cannot responsibly provide.

CTE is a progressive neurodegenerative disease associated with prior exposure to RHI and characterized neuropathologically by the accumulation of hyperphosphorylated tau in a distinctive perivascular distribution [2, 3, 6, 7]. At present, it can only be definitively diagnosed postmortem. Recent neuropathological investigations have further demonstrated the burden of CTE among former professional American football players, with evidence linking advanced CTE pathology to dementia [8]. However, substantial uncertainty remains regarding the prevalence of CTE across exposed populations and the relationship between neuropathological findings and clinical manifestations during life [9]. Despite substantial efforts toward biomarker development, no validated in vivo diagnostic framework currently exists [10]. Although consensus research criteria for traumatic encephalopathy syndrome (TES) have been proposed to characterize the potential clinical manifestations of CTE [11], recent clinicopathological evidence has raised concerns regarding their diagnostic specificity. In a study of 1038 neurodegenerative brain-bank cases, 25 individuals met TES criteria, of whom only six (24%) demonstrated CTE neuropathologic change, with diagnostic performance largely driven by RHI exposure rather than the proposed clinical features [9]. Similarly, in a community-based cohort of 295 individuals with traumatic brain injury (TBI), 33.5% met all core clinical features of TES when the RHI exposure requirement was excluded, with no significant differences between those with and without RHI exposure [12]. Together, these findings raise important concerns about the specificity of the proposed clinical features of TES and reinforce the challenges of identifying CTE during life. This gap between neuropathologic definition and in vivo identification represents one of the central translational challenges in contemporary CTE research.

Public Awareness and Clinical Uncertainty

These clinical encounters reflect a broader shift in how former athletes understand and interpret the potential long-term consequences of RHI [5]. In the public imagination, CTE has evolved from a neuropathologic diagnosis into a living explanatory framework for persisting cognitive, behavioral, and functional symptoms following RHI [13–15]. CTE has emerged into public consciousness faster than neuroscience has developed reliable methods for identifying the disease during life, creating a widening gap between patient expectations and current clinical capability [14]. This gap has fundamentally changed the nature of athlete care. Clinicians are asked not only to manage persisting symptoms after RHI but also to counsel former athletes seeking certainty about the underlying causes of their symptoms, their future neurological health, and whether they have a disease, often characterized as relentlessly progressive, that remains impossible to diagnose during life.

For clinicians caring for former athletes, these encounters present challenges that extend beyond the traditional evaluation and management of concussion. Concussion centers have traditionally focused on the evaluation and management of acute and subacute injury [16]. They now also encounter more complex, longitudinal presentations shaped by overlapping neurologic, psychiatric, and social factors. Many interdisciplinary concussion centers have long incorporated integrated approaches to care and continue to expand these models to address the evolving complexity of patient presentations [16]. As the clinical landscape shifts, there is a growing need for frameworks that better integrate diagnostic uncertainty, interdisciplinary care, and complex neurobehavioral presentations.

What makes these encounters particularly challenging is not only the complexity of symptoms but also the growing cultural authority of a diagnosis that remains pathologically defined. CTE now occupies a unique place in medicine: it is simultaneously one of the most publicly recognized neurodegenerative conditions and one of the least clinically diagnosable. Public understanding of CTE has been shaped by extensive media coverage, which has contributed to heightened awareness of the potential long-term consequences of RHI [17]. However, greater awareness does not necessarily translate into an accurate understanding of the scientific evidence [14]. Patients often arrive having absorbed a powerful explanatory

framework from media coverage, documentaries, legal proceedings, and personal networks [13, 15, 18, 19]. Research examining public knowledge of CTE has identified important gaps in understanding [14], underscoring the challenges clinicians face when addressing established beliefs about the disease. By the time they enter the exam room, some patients may be seeking confirmation of a conclusion they have already reached rather than an open exploration of possible explanations for their symptoms.

Clinical Implications of Diagnostic Uncertainty

This shift has practical consequences. Diagnostic uncertainty, when it collides with fixed expectations, can rapidly become distressing for patients whose symptoms may be influenced by chronic pain, psychiatric illness, sleep disruption, polypharmacy, or traumatic life experiences [5, 20–28]. From the patient's perspective, a clinician's inability to provide definitive answers may be perceived as dismissal or a lack of expertise. The encounter becomes burdened not only by neurologic symptoms but also by fear, identity, and prognosis. In this setting, frustration can escalate quickly, creating challenges for patients, clinicians, trainees, and staff alike.

For many former athletes, concern about CTE extends far beyond the question of whether the disease is present. Fear of progressive cognitive decline may influence mental well-being, retirement adjustment, family relationships, employment decisions, and willingness to engage with healthcare [29]. This fear may also carry its own risk. Although suicide has frequently been linked to CTE in public discussions, postmortem research in contact-sport athletes has not identified a significant association between CTE neuropathology and suicide as a cause of death [8, 30]. However, depression and anger-control problems can resemble the proposed clinical features of CTE, creating substantial potential for misattribution [31]. Among living former professional football players, those who believed they had CTE were approximately twice as likely to report suicidality, even after accounting for depression and other established predictors [5]. Although this association does not establish causality, it underscores the importance of assessing psychological distress and suicidality among athletes concerned about CTE. In this context, the clinical encounter becomes more than a diagnostic evaluation; it becomes an opportunity to acknowledge uncertainty, address fear and misconceptions, provide context for current scientific evidence, and identify evidence-based strategies that support long-term brain health regardless of whether CTE neuropathological change can be confirmed. Importantly, the absence of a definitive diagnostic test does not preclude meaningful clinical evaluation or intervention. By shifting the focus from diagnostic certainty to comprehensive athlete-centered care, clinicians can help patients navigate uncertainty while maintaining trust and promoting meaningful interventions that improve overall health and quality of life.

Navigating Diagnostic Uncertainty Through Interdisciplinary Care

Meeting these broader needs often requires care that extends beyond any single specialty. Patients with histories of RHI are often evaluated across multiple specialties based on their presenting symptoms, but outside of specialized interdisciplinary programs, such as concussion centers, these evaluations may occur independently, with limited communication or coordination across specialties. While these approaches address important aspects of care, they may not always fully capture the broader concerns driving presentation, including how patients interpret their symptoms in the context of feared neurodegeneration. This challenge reflects not a failure of existing care models, but the need to align established models of interdisciplinary care with evolving patient expectations and diagnostic uncertainty. Interdisciplinary concussion programs are continuing to adapt to these realities, expanding to incorporate neuropsychiatric care, longitudinal management strategies, and coordinated approaches to complex neurobehavioral presentations [16]. These efforts reflect an important shift from managing isolated symptoms to providing coordinated, longitudinal care that addresses both clinical symptoms and the uncertainty surrounding their underlying causes.

An important component of caring for athletes concerned about CTE is recognizing that diagnostic uncertainty does not preclude meaningful clinical intervention. Rather than approaching these encounters solely as attempts to confirm or exclude CTE, clinicians can begin by identifying the specific concerns motivating the consultation, whether these involve current symptoms, fear of future cognitive decline, or uncertainty about the long-term consequences of RHI. This distinction allows clinicians to address symptoms that warrant evaluation and treatment while separately discussing the substantial uncertainty surrounding an individual's future risk of CTE. Patients may also ask about imaging or blood-based tests for CTE. Although these are active areas of research, no imaging or fluid biomarker is currently validated for diagnosing CTE in individual patients, and these measures should not be interpreted as confirming or excluding CTE in clinical practice [1]. Shared decision-making provides a useful framework for these discussions by integrating the best available scientific evidence with patients' values, preferences, and individual circumstances [32]. Within this framework, clinicians can

acknowledge the limitations of current diagnostic methods while collaboratively identifying priorities for evaluation and management. Motivational interviewing may further support these conversations by helping patients explore concerns, address ambivalence, and identify achievable health-related goals [33]. Family members may also play an important role in these encounters, particularly when they have observed changes in cognition, behavior, or daily functioning. With the athlete's consent, involving family members can provide valuable collateral history, clarify shared concerns, and support discussions about ongoing care and future planning. Importantly, these approaches shift the clinical encounter away from the pursuit of diagnostic certainty and toward a collaborative process in which patients remain actively engaged in decisions about their health.

Beyond communication, the clinical evaluation should prioritize identifying potentially treatable contributors to the symptoms that prompted the consultation. Cognitive complaints, mood disturbances, sleep difficulties, headaches, chronic pain, and changes in daily functioning warrant careful assessment rather than being attributed prematurely to an underlying neurodegenerative process. A comprehensive evaluation should consider neurological and psychiatric conditions, medication effects, sleep disorders, and other medical or psychosocial factors that may independently or collectively contribute to the clinical presentation. A structured, lifetime head trauma history, capturing both RHI and individual TBIs across sport and non-sport contexts, may further help contextualize symptoms, as chronic sequelae of TBI can overlap with the proposed clinical features of CTE [34, 35]. When appropriate, neuropsychological assessment and targeted referrals to neurology, psychiatry, sleep medicine, rehabilitation, or other specialties can help clarify the nature of these concerns and guide individualized management. Importantly, clinicians should avoid equating a history of RHI or the presence of non-specific symptoms with evidence of CTE. The absence of a validated diagnostic test should not become a barrier to addressing symptoms, treating identifiable conditions, or establishing longitudinal follow-up. Clinicians can also address modifiable risk factors for later-life cognitive decline, including hypertension, physical inactivity, excessive alcohol consumption, hearing loss, social isolation, and depression, while evaluating and treating sleep disorders and other conditions that may contribute to current symptoms [36]. These approaches offer athletes concrete opportunities to support their neurological and overall health, regardless of the uncertainty surrounding their individual risk of CTE. In this way, clinical care can remain both scientifically grounded and therapeutically meaningful, even when the underlying neuropathological diagnosis remains uncertain.

Although these challenges are particularly evident among former athletes, concerns about CTE may also influence clinical encounters with athletes who remain actively engaged in contact and collision sports. For these individuals, uncertainty about the long-term consequences of RHI may shape decisions about continued participation, recovery following concussion, and return-to-sport. These conversations require clinicians to distinguish between the established principles guiding the management of sport-related concussion and the unresolved question of an individual's future risk of developing CTE [37, 38]. Decisions about return-to-sport following concussion should remain grounded in current consensus recommendations, clinical recovery, and individualized assessment rather than assumptions about the presence or future development of CTE [38, 39]. Decisions about continued participation in contact or collision sports, however, may require a broader discussion of cumulative exposure, uncertain long-term risks, and the athlete's personal priorities and risk tolerance, guided by shared decision-making. Such discussions may be relevant across contact and collision sports, as well as among tactical populations exposed to RHI, underscoring that the clinical challenges posed by CTE-related concerns extend beyond former American football players.

The stakes extend beyond individual encounters. As clinicians navigate the growing intersection of RHI exposure, concerns about neurodegeneration, and complex neurobehavioral symptoms, the challenge is not simply to expand access to specialized care but also to ensure that care remains coordinated, evidence-based, and responsive to diagnostic uncertainty. At the same time, this evolving clinical landscape presents an opportunity to redefine how medicine approaches chronic symptoms after RHI and to develop care models that better align with the realities of both patients and providers. Although the approaches outlined here draw on established principles of clinical care, evidence regarding their effectiveness specifically among athletes concerned about CTE remains limited. Future research should examine how these communication and care strategies influence psychological distress, healthcare engagement, and suicidality among athletes concerned about CTE.

Conclusion

The athlete who asks, "Do I have CTE?" is not simply asking for a diagnosis. They are asking medicine to explain suffering in the face of uncertainty. How medicine responds to that question may shape not only the future of brain injury care but also how clinicians navigate

diseases whose cultural visibility has outpaced diagnostic certainty.

Abbreviations

CTE Chronic traumatic encephalopathy
RHI Repetitive head impacts
TBI Traumatic brain injury
TES Traumatic encephalopathy syndrome

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Author details
[1]Department of Neurology, NYU Grossman School of Medicine, New York, NY, USA. [2]NYU Langone Concussion Center, NYU Langone Health, 240 East 38th Street, 17th Floor, New York, NY 10016, USA. [3]Department of Rehabilitation Medicine, NYU Grossman School of Medicine, New York, NY, USA. [4]Brain Injury Research Center, Icahn School of Medicine at Mount Sinai, New York, NY, USA. [5]Department of Rehabilitation and Human Performance, Icahn School of Medicine at Mount Sinai, New York, NY, USA. [6]Nash Family Department of Neuroscience, Icahn School of Medicine at Mount Sinai, New York, NY, USA. [7]Friedman Brain Institute, Icahn School of Medicine at Mount Sinai, New York, NY, USA. [8]Institute for Translational Neuroscience, NYU Grossman School of Medicine, New York, NY, USA.

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