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Primum non nocere: a call for balance when reporting on chronic traumatic encephalopathy

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As clinicians and researchers in traumatic brain injury and neurodegeneration we are concerned by the tone of reporting on chronic traumatic encephalopathy (CTE) that has developed in the past decade, highlighted in a recent article in the New York Times[1]. Misleading reporting can have unintended, negative consequences and we call for balance from the medical and scientific communities and the media when communicating on issues related to CTE.

Contrary to common perception, the clinical syndrome of CTE has not yet been fully defined[2], its prevalence is unknown and the neuropathological diagnostic criteria are no more than preliminary[3]. Crucially, we have incomplete understanding of the extent or distribution of pathology required to produce neurological dysfunction or to distinguish disease from normality, with the neuropathologic changes of CTE reported in apparently asymptomatic individuals[4,5]. Finally, although commonly quoted, there remains no consensus agreement on staging the severity of CTE pathology. In short, a single focus of the pathology implicated in CTE is not yet sufficient evidence to define disease.

Recognizing limitations of the diagnostic process in human pathology, pathologists are careful to note that they are merely providing an opinion; acknowledging that another pathologist might reasonably reach a different conclusion on the same case[6]. In diagnoses where the criteria for assessment and reporting are established by broad consensus, the expectation is that variance in opinion is minimised. At this time, however, while CTE diagnostic criteria remain far from established, it is to be expected that there will be discordance in opinions on individual cases[1].

Unfortunately, the uncertainties around the clinical syndrome and the pathological definition of CTE are not acknowledged adequately in much of the current research literature or related media reporting, which at times has resembled ‘science by press conference’[7]. Too often an inaccurate impression is portrayed that CTE is clinically defined, its prevalence is high and pathology evaluation is a simple ‘positive’ or ‘negative’ decision. This distorted reporting on CTE may have dire consequences. Specifically, individuals with potentially treatable conditions, such as depression or post-traumatic stress disorder, might make decisions on their future based on a misplaced belief that their symptoms inevitably herald an untreatable, degenerative brain disease culminating in dementia.

We propose that the principle of ‘first, to do no harm’ is employed when communicating on CTE, whatever the platform. In particular, the many remaining uncertainties should always be acknowledged. Otherwise, there is a distinct risk of doing very real harm.

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