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Brain Donation Among the DV-TBI Population: Call to Action

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The first publicly known domestic violence (DV)—related chronic traumatic encephalopathy (CTE) case was in 2023. This particular DV female case received wide scientific attention because, to date, it was found to be the most severe case of CTE and Alzheimer's disease (AD) by the largest tissue repository in the world focused on traumatic brain injury (TBI) and CTE. This woman is my beloved mother.

I realized my mother had CTE during the 1970s. However, decades later when she was under my care, I was routinely dismissed by her neurologists when I shared her forty years of head trauma history as a result of DV. They diagnosed her with moderate to severe AD. I agreed but insisted her symptoms were not all associated with AD – something else was going on. When my mother passed, I decided to donate her brain to learn the extent of her head trauma.

Dr. Ann McKee shared the results of my mother's neuropathology results, remarking, "Alzheimer's and CTE were both very severe by the time of death, and compounding that is just this incredible loss of nerve cells and white matter fibers, the likes of which I've never seen in CTE or in Alzheimer's disease… I don't know how your mother was functioning."

Health and System of Care Service Gap

While alive, my mother did not know the numerous symptoms she was experiencing were related to CTE, AD, traumatic brain injury (TBI), or other head trauma due to the domestic violence she experienced throughout her forty plus years of marriage. Hence, she did not understand the importance of seeking medical care nor donating her brain to advance the science of DV-CTE. My mother is not an isolated case. In fact, the DV population is largely unaware they may be experiencing a multitude of symptoms as a result of head trauma due to abuse, and this brain injury, including repeated head impacts, can result in catastrophic health consequences such as CTE and/or other progressive neurodegenerative diseases. [1]

Moreover, DV services have historically failed to reach or meet the needs of ethnic and racial minority victims due to white feminism excluding them from the Battered Women's Movement. [2] Researchers, scholars, advocates, and practitioners have advocated and documented the importance of intentionally and strategically integrating cultural and linguistic responsiveness modalities [3] as well as addressing the underlying intersectionalities and structural inequalities [4] impacting diverse DV victims within the DV service provision to help them. This lack of service model is an underlying systemic barrier for culturally diverse women like my mother who told me that DV services in the United States (U.S.) were not developed nor intended for her as I pleaded with her to get help.

To compound this public health crisis, we have a DV population overall unaware of their risk for head injury and consequently, CTE. There are no inclusive targeted national, state, nor local campaigns aimed at creating awareness and educating the DV population about head injury, its symptoms, where to get assessed and treated, resources for families, or where to participate in clinical studies. Making matters worse is that the system of care, judicial system, first responders, the healthcare field, and other front-line providers are often unaware of the relationship between head trauma and DV. This means that the few DV survivors who seek help often go undiagnosed [5] or misdiagnosed, their symptoms dismissed as mental health issues such as depression, anxiety, or post-traumatic stress disorder (PTSD). [6,7]

My mother's experiences illustrate this systemic failure. As an immigrant woman from Mexico who did not speak English, she felt DV services in the U.S. were not designed for her. Despite all her seven children attaining higher education, she could not access care that addressed her needs.

I, too, was dismissed by neurologists when I pleaded with them to factor in her four decades of head trauma. They concluded she had moderate to severe AD—they were wrong.

Millions of individuals face challenges like my mother's, unable to fully participate in daily living like work, school, caring for children, and family life due to DV-head trauma and potentially DV-CTE. These survivors often experience cognitive, physical, mood, and behavioral symptoms that hinder their ability to function, which can result in homelessness, further trauma, or exclusion from the system of care and other fields. Moreover, ethnic and racial minorities often face additional barriers due to systemic racism and the historical exclusion of marginalized communities from DV advocacy efforts.

Despite the prevalence of DV in the U.S. and globally, research into its link with head trauma remains sparse. There is no comprehensive strategy to scientifically understand the overall impact of head trauma on the DV population, develop treatments, or identify biomarkers for diagnosis in the living. To advance this field, we must study more DV-head trauma and DV-CTE-affected brains, like my mother's. We also need to incorporate available DV-TBI data which does not account for ethnic and racially diverse women, women with abusive histories (or women who abuse their male partners) nor male DV victims, youth DV victims, or other DV cohorts.

Brain Donation: A Precious, Meaningful, and Consequential Gift

Making the decision to donate my mother's brain was not an easy one, but it was critical and necessary for future generations of DV-TBI and potentially DV-CTE victims and survivors and the global society. Brain donation is a key mechanism for advancing our knowledge of brain function and disease progression, especially in diseases like CTE which cannot be diagnosed in life, leading to potential breakthroughs in treatment development. Sadly, most brain banks in the world are not educating the DV-TBI population about the urgency and significance of brain donation. It is not enough for brain banks to assume the DV population understands the significance of brain donation as they are unaware of their risk for CTE and do not realize the importance of brain donation. For marginalized individuals, like my family, health disparities and intersectionality further isolate and prevent us from receiving critical information, so it is vital that brain donation outreach be framed culturally and linguistically responsive in all communities. It is time we reverse this trajectory and follow the steps of the BU CTE Center, the first brain bank encouraging brain donation among the DV population with sensitivity as well as with cultural responsiveness.

Despite available data on DV and TBIs, there are no inclusive, culturally responsive educational campaigns at any level to proactively address this issue across the DV population. This means the DV population as a whole is unaware of their risk for head trauma and CTE. We must sound the alarm to encourage brain donation among the DV population and address the systemic barriers preventing these individuals from accessing care.

I knew what I had to do upon learning my mother's results: dedicate my life to creating awareness about DV-head trauma and CTE and the importance of brain donation so that other individuals and families, like mine, do not face the barriers we confronted. I am hopeful and faithful that more treatments will be developed to stop CTE disease progression and be able to diagnose it among the living.

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