

Living “The Social Life of TBI”: On the Value of Embodied Research

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Project Summary

As an anthropology PhD candidate and TBI survivor researching my own disability for my dissertation, I draw heavily on my own experience. My advisors questioned this approach, requiring me to extensively observe and document it. I compare these observations to my field data to assess the value of embodied research and draw implications for Social Science and Disability Studies of TBI.

Background definitions

A Traumatic Brain Injury (TBI) is caused by a *physical* head injury

- Leads to diverse physical, emotional, and cognitive impairments
- More than 2.5 million TBIs sustained in 2013 (CDC 2015)
- Correlated with isolation, poverty, homelessness (Gainer 2018)
- Few social scientific studies of TBI as a disability

Embodied Research blurs relations between researcher and subject

- When scholars themselves embody what they study (Spatz 2017)
- May include but *is not* memoir, autoethnography, or un-scientific
- Common in Disability Studies, rare in the social sciences

The Social Life of TBI is my NSF-sponsored dissertation on the embodied and socially constructed meaning of TBI in the US

Centers for Disease Control and Prevention (CDC 2015). *Report to Congress on Traumatic Brain Injury in the United States: Epidemiology and Rehabilitation*. Atlanta: National Center for Injury Prevention and Control, Division of Unintentional Injury Prevention.

Gainer, Rolf (2018). Finding the Self and Social Role Return. Presentation at Washington State 2018 Traumatic Brain Injury Conference in Tacoma, WA.

Spatz, Ben (2017). Embodied Research: A Methodology. *Liminalities: A Journal of Performance Studies* 13(2).

Methods

I kept a **reflexive journal** documenting my 5 years as a graduate student, AUCD Diversity Fellow, and ethnographer. I then compared this journal with ethnographic data from my fieldwork:

- 75 interviews of survivors, those close to them, and policymakers
- 10 months’ participant-observation of NGOs and Support Groups
- Numerous TBI policies and programs in my field site

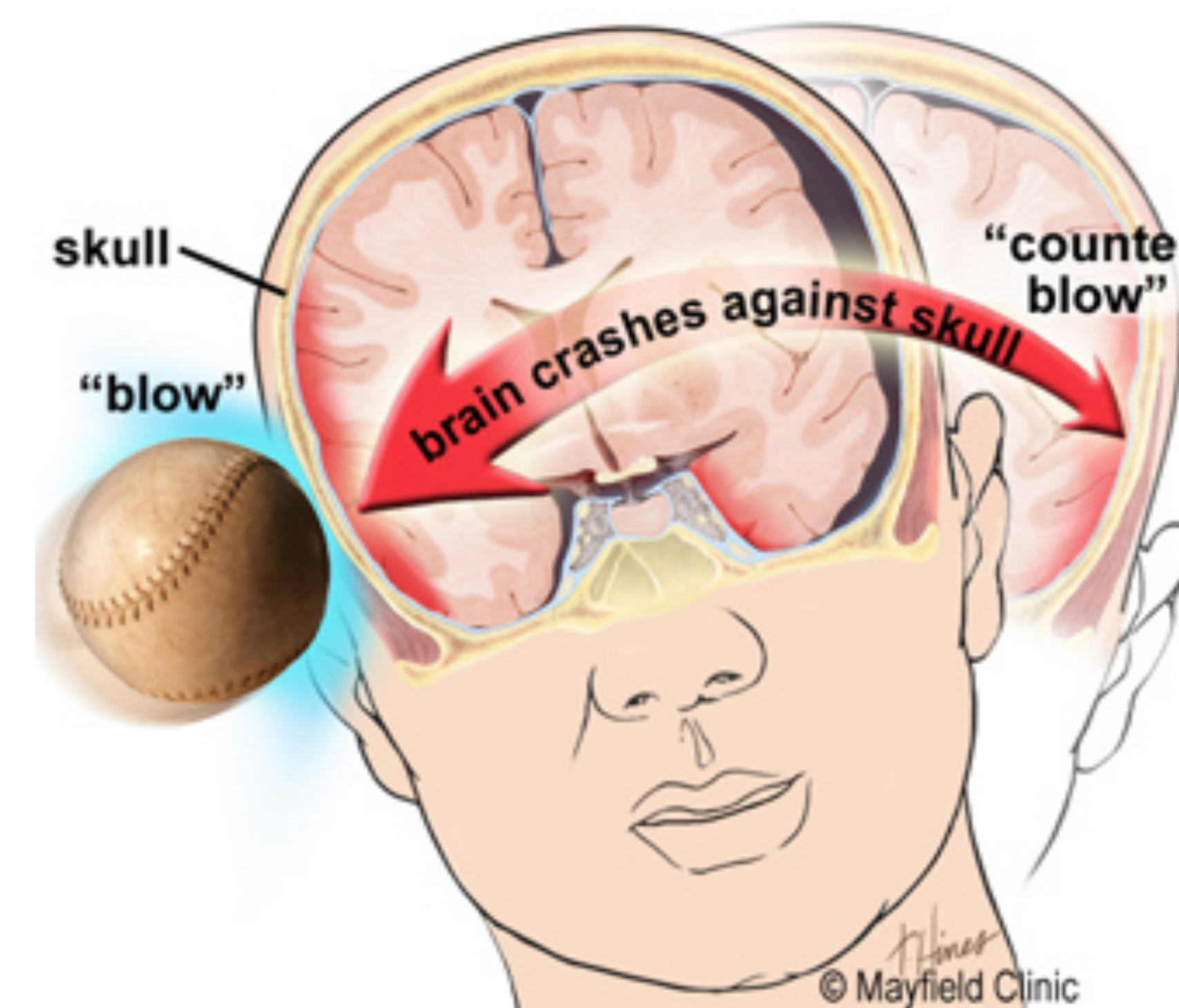
My TBI experience

In 2003, I sustained a severe TBI from a traffic accident

- “Blow”: Left Frontal Lobe (emotion, reasoning, memory)
- “Counter blow”: Right Temporal Lobe (vision, language)
- Global Effects (balance, coordination, attention, fatigue, etc)

Impairments continue to impact my life and academic career today

- Safely conducting basic Activities of Daily Living
- Developing an identity as both disabled *and* a social scientist
- Navigating professional and personal relationships
- Connecting to a diverse, marginalized, disability community



A TBI results from a physical injury of the head at one moment in time <https://www.mayfieldclinic.com/PE-TBI.htm>



Brain Injury survivors coming together to form a community identity <https://www.biawa.org/images/resources.jpg>

Findings

My TBI experience led me to develop novel research questions

- What does it mean to live “with TBI” when all TBIs are different?
- What role do others play in survivors’ experience with disability?

Being disabled by a TBI proved essential to my ongoing fieldwork

- 1: **Access** to survivors, families, organizations, and state policies
- 2: **Insight** into behaviors that would otherwise be inexplicable
- 3: **Credibility** among survivors, their significant others, and policymakers, who expressed relief that I “got it.”

But my impairments continue to hamper my research, as well

- **Physical** (double vision, ataxia, fatigue)
- **Emotional** (anxiety, impulsivity, mood swings)
- **Cognitive** (concentration, executive functioning, memory)
- **Perceptions** of my TBI cloud my relations within academia and can exacerbate *and be exacerbated by* the above

Conclusions/Implications

Embodied Methods played a key role in my research:

- Developing research questions and enhancing data collection
- Unaccommodated impairments limit my effectiveness

Embodied and Traditional Methods should be harnessed together:

- Teams-based social science can benefit from disabled researchers’ strengths while accommodating their impairments
- Complimentary studies can approach the same research from impaired and un-impaired perspectives

Disability Studies paradigms should be adapted to account for TBI and other impairments that do not fit within its traditional model

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Also, this project belongs to the many millions of unacknowledged TBI survivors throughout the country. I will count it successful if it spreads even a little awareness of our exceptional and particular disability as one that is indelibly human and increasingly common.

