

Why Self-Report?

[Abridged and adapted from Corrigan, J. D., Bogner, J. (2007). Screening and identification of TBI. Journal of Head Trauma Rehabilitation, 22(6), 315-317.]

The literature in traumatic brain injury (TBI) research is dominated by cohorts for which the TBI (or its absence) was determined at the time that medical attention was given. Whether samples are collected prospectively or retrospectively from a given point in the system of care (e.g., Emergency Department admissions; patients treated in rehabilitation), the standard for description relies on indicators reflecting the extent of altered consciousness as observed by professionals who treated the acute injury (e.g. first GCS in the Emergency Department; time to follow commands during acute hospitalization). Even studies from later in the process of treatment identify a sentinel occurrence of a TBI (e.g., six months post severe TBI), and whenever possible report the altered consciousness observed at the time (e.g., with five days of post-traumatic amnesia). Even the epidemiological data in our field is dominated by reports of incident cases, most commonly identified by the ICD-9 code given at the time of treatment. When the methodology shifts to identifying TBI in cohorts defined not by having been treated, but by some other criteria (e.g., school children with behavioral problems, nursing home residents, prisoners, clients treated for substance abuse disorders or soldiers returning from combat) then the ways of detecting and categorizing TBI to which we are so accustomed are no longer available.

A first reaction to this state of the practice is, “why not just collect information about past TBI’s from previous medical records.” This is a logical approach, and if it were only time-consuming (which it would be) someone would have done it. Indeed, it borders on impractical to attempt to find the facilities that provided all of a person’s prior treatments and then gain access to those medical records. Perhaps at some time in the future our medical records will be in a single location, but for now there is no way of determining a person’s prior treatments without asking him or her to identify them. Putting aside the issue of self-report for the moment, the ability to actually obtain a lifetime’s worth of medical records for injuries treated in physicians’ offices, Emergency Departments or hospitals is a daunting task without adding those injuries attended to only by a school nurse, athletic trainer or Emergency Medical Technician in the field. But obtaining all these medical records is only what makes the task impractical. What makes it impossible to use medical records to study a past history of TBI is the significant proportion of these injuries that receive no medical attention at all. Diamond and colleagues reported that 61% of head injuries among prisoners are untreated¹; similarly, Corrigan and Bogner found that 30% of TBI’s experienced by persons with co-morbid substance use disorders did not receive medical attention². Setnik and Bazarian reported that 42% of persons responding to a web-based survey had experienced TBI without any medical attention³. In other projects we have found 25% of adolescents in treatment for substance use disorders report prior TBI with loss of consciousness for which they received no medical attention of any kind; and 41% of TBI’s reported by prisoners received no medical care (J. D. Corrigan & J.A. Bogner, personal communication, September, 2007). Quite clearly, if not treated there will not be a medical record to obtain.

The second thought that often comes to mind when faced with the dilemma of identifying past TBI is to conduct testing. However, there is no biomarker or other definitive test for TBI. Techniques like CT scans MRI, DTI, PET scanning or neuropsychological assessment can be used to detect acute TBI of sufficient severity, or chronic TBI of greater severity, but none of these techniques are sensitive to all TBI, especially not all TBIs that may have occurred over a person's lifetime. The validity of our customary assessment techniques is due to their specificity (an abnormal finding is highly likely to be an incident case) but not their sensitivity (a normal finding means no TBI ever occurred). Very mild (transient confusion without loss of consciousness) or very old (a TBI experienced in childhood) injuries are the most likely to be missed. Further, despite exciting work being conducted using proteomics, imaging, EEG recordings and even eye movements, we are still without a definitive biomarker of TBI. Thus, once again, to establish prevalence of TBI in a population (or eventually, the general population), or conduct research comparing those members of a cohort with and without TBI, requires different approaches to case identification than research on incidence or studies of samples collected from treatment settings.

Thus, the gold standard for determining prior TBI is self-report as determined via structured or in-depth interview. While this statement may seem radical, it indeed reflects the standard of clinical care and research. When we look back before a sentinel TBI that has led to a current episode of treatment, we use a clinical interview of patients or their proxies to determine if there was a prior history of TBI. Research reports often cite prior TBI as an exclusionary criterion; however, after conducting our own research on methods of eliciting prior history, we find these claims far more suspect than when we were naive about the challenges of eliciting self-report. Indeed, not all self-report is created equal. One or two items in a self-administered scale or structured telephone survey will miss all but the most recent or most severe TBI's. In public health research the tendency to forget past injuries is called telescoping^{4,5}. Diamond and colleagues found that a one-item, self-administered screener used during admission to prison detected only 19% of the TBI's identified via structured interview¹. Self-report also varies by the extent to which the respondent must self-diagnose whether the injury occurred. Whether "head injury" or "traumatic brain injury"; "lost consciousness" or "knocked out", each of these terms requires a minimum amount of knowledge on the part of the respondent; and, quite likely, more than a minimum if we expect their response to correspond with our presumptions about their responses. There is no question that self-report leaves much to be desired; however, a face-to-face interview conducted in a standardized manner by a trained interviewer or informed professional is indeed the gold standard for determining lifetime history of TBI.

References

1. Diamond, PM, Cumming, AG, Magaletta, PR, Frankowski, R, Levin, H, Pedrosa, C. Screening for traumatic brain injury in a sample of federal offenders: A first look at the reliability and validity of the Traumatic Brain Injury Questionnaire (TBIQ). *J Head Trauma Rehabil.* 2007; 330-338.
2. Corrigan, JD, Bogner, JA. Initial reliability and validity of the OSU TBI Identification Method. *J Head Trauma Rehabil.* 2007; 318-329

3. Setnik L, Bazarian JJ. The characteristics of patients who do not seek medical treatment for traumatic brain injury. *Brain Inj.* 2007;21(1):1-9.
4. Warner M, Barnes PM, Fingerhut LA. Injury and poisoning episodes and conditions: National Health Interview Survey, 1997. *Vital Health Stat* 10. 2000;10(202):1-3.
5. Warner MPM, Schenker N, Heinen MA, Fingerhut LA. The effects of recall on reporting injury and poisoning episodes in the National Health Interview Survey. *Inj Prev.* 2005;11:282-287.