

Accuracy of Self-report as a Method of Screening for Lifetime Occurrence of Traumatic Brain Injury Events that Resulted in Hospitalization

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Abstract

Background: Traumatic brain injury (TBI) occurs frequently during child and early adulthood, and is associated with negative outcomes including increased risk of drug abuse, mental health disorders and criminal offending. Identification of previous TBI for at-risk populations in clinical settings often relies on self-report, despite little information regarding self-report accuracy. This study examines the accuracy of adult self-report of hospitalized TBI events and the factors that enhance recall. **Methods:** The Christchurch Health and Development Study is a birth cohort of 1265 children born in Christchurch, New Zealand, in 1977. A history of TBI events was prospectively gathered at each follow-up (yearly intervals 0–16, 18, 21, 25 years) using parental/self-report, verified using hospital records. **Results:** At 25 years, 1003 cohort members were available, with 59/101 of all hospitalized TBI events being recalled. Recall varied depending on the age at injury and injury severity, with 10/11 of moderate/severe TBI being recalled. Logistic regression analysis indicated that a model using recorded loss of consciousness, age at injury, and injury severity, could accurately classify whether or not TBI would be reported in over 74% of cases. **Conclusions:** This research demonstrates that, even when individuals are carefully cued, many instances of TBI will not be recalled in adulthood despite the injury having required a period of hospitalization. Therefore, screening for TBI may require a combination of self-report and review of hospital files to ensure that all cases are identified. (*JINS*, 2016, 22, 717–723)

Key words: Brain injury, Head injury, Concussion, Self-report, Recall, Accuracy, Cohort, Prospective

INTRODUCTION

Traumatic brain injury (TBI) is a frequent event throughout the life span, with an annual incidence rate of 1.7 million in the United States alone (Daneshvar et al., 2011). Traumatic brain injury is particularly prevalent during early childhood through to young adulthood (0–25 years) (Feinstein, Hershkop, Jardine, & Ouchterlony, 2000; McKinlay et al., 2008). There is increasing evidence that early TBI is associated with deficits in several areas including cognition, behavior and mental health. While severity of injury has an important impact on outcomes, less severe injuries are also associated with cognitive and behavioral deficits (McKinlay,

Corrigan, Horwood, & Fergusson, 2014; Timonen et al., 2002; Williams, Cordan, Mewse, Tonks, & Burgess, 2010).

Furthermore, the consequences of even mild TBI (mTBI) may be long lasting and impact on educational and social functioning (Hessen, Nestvold, & Anderson, 2007; McKinlay, Dalrymple-Alford, Horwood, & Fergusson, 2002; Timonen et al., 2002; Williams, Mewse, et al., 2010). It is not surprising therefore that a significant number of individuals with a history of TBI will require support and therapeutic input at some time post-injury. However, research suggests outcomes from TBI are often not attributed to the event (Hawley, Ward, Magnay, & Long, 2002; Hawley, Ward, Magnay, & Mychalkiw, 2004), and there is little information regarding how accurate individuals are at recalling occurrences of TBI. It is important that we understand what influences personal recall to develop methods to accurately elicit historic TBI identification.

There is considerable research that suggests that TBI is associated with negative outcomes that are likely to

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require intervention. For example, McKinlay et al. (2010) reported that individuals who had an early TBI that required hospitalization were significantly more likely to have symptoms consistent with attention deficit hyperactivity disorder, conduct disorder, and substance abuse. Furthermore, among this group of individuals, early injury was associated with an increased risk of property offenses, criminal offending, and violent behavior when they were assessed during early adulthood (McKinlay, Grace, Horwood, Fergusson, & MacFarlane, 2009).

Other negative outcomes have also been reported following TBI, particularly among high-risk groups, such as prison populations (Corrigan, Selassie, & Orman, 2010; Dams-O'Connor et al., 2014; McKinlay, Van Vliet-Ruissen, & Taylor, 2014). For example, a recent meta-analysis examining literature of adult offender population found that the estimated prevalence of prior TBI among offenders was 60.4% compared to 8.5% among the general public (Shiroma, Ferguson, & Pickelsimer, 2010). Furthermore, inmates with TBI were found to have a higher rate of disciplinary incidents and were slower to adapt to prison rules (Shiroma et al., 2010). Effective intervention for individuals with TBI within the prison system and community will require identification that the event occurred, and a tailoring of intervention strategies to meet the needs of this group, particularly as many may have deficits in attention, concentration, and executive functions.

A review of hospital files will usually not be possible, and many of the TBI events will not have received medical treatment, particularly among high-risk groups (Diamond, Harzke, Magaletta, Cummins, & Frankowski, 2007). Therefore, identification will usually rely on personal recall of events. Recall is likely to be affected by the age at which the event occurred, number of years post event, and the significance of the event to the individual or their family. Research suggests that generally, very early events tend not to be recalled due to childhood amnesia (the inability of adults to retrieve episodic memories before the age of 2–4 years) (Bruce, Dolan, & Phillips-Grant, 2000). Childhood amnesia is followed by increasing ability to recall personal events (Bruce et al., 2000).

We have previously investigated memory (0–9 years of age) for early childhood mTBI and found a very low level for recall for injuries that did not require hospitalization, that is, seen by their general practitioner or in the Emergency Department and discharged with no further input (McKinlay, Horwood, & Fergusson, 2016). Research suggests that more significant events in a child's life become part of what is rehearsed in the family and become known by the individual, even though they might have no personal memory of the event (Bruce et al., 2000). Therefore, it might be expected that more severe injury (of sufficient severity to warrant an inpatient stay) would be more likely to be recalled, either *via* personal memory, or by reports from other family members, because the stress associated with a hospitalized is likely to make the event more memorable (Bruce et al., 2000).

Other groups point to the importance of careful questioning regarding the incidence of TBI to elicit recall (Diamond et al., 2007). For example, a single question may be misinterpreted by the informant (self or significant other), depending on whether there is sufficient cueing to enhance recall. Corrigan and colleagues (2010) point out that one or two items on a self-report is likely to underestimate lifetime exposure of TBI events, and that questioning by a trained interviewer is likely to increase recall (Corrigan et al., 2010). Furthermore, terminology used may result in low recall as the general public are not always aware of similarity/differences between terms such as head injury, brain injury, and concussion (Corrigan & Boger, 2007; McKinlay, Bishop, & McLellan, 2011).

It is clear that identifying TBI events may be important for rehabilitation. However, self-report is commonly the only way in which a life-time history of TBI can be elicited, and there is little information about the accuracy of this method of identification even when memory is cued and information is elicited by a trained interviewer.

This study examined adult recall (at 25 years of age) for all hospitalized TBI events (0–<25 years) that occurred in the Christchurch Health and Development Study. We hypothesized that recall for TBI events would increase as the time post-injury decreased. This study also examined the influence of injury severity on recall of TBI. We hypothesized that more severe injuries and loss of consciousness (LoC) would increase recall for an injury event.

METHODS

The data were gathered as part of the Christchurch Health and Development Study (CHDS), a 35-year longitudinal study of a birth cohort of 1265 children born in Christchurch (New Zealand) during mid-1977. These children represented 97% of all births occurring in Christchurch during the recruitment period for the study. Cohort members have been studied at birth, 4 months, 1 year and at yearly intervals to age 16, then again at ages 18, 21, and 25 years. Injury information has been collected at each of the follow-up periods. Due to attrition (as a result of death, refusal, or loss to follow-up) the initial cohort of 1265 children had reduced to 1003 by age 25 years (79.3% of the initial cohort) (Fergusson, Horwood, & Lloyd, 1991; Fergusson & Lynskey, 1998).

Data for the cohort have been gathered using information from a combination of sources including: parental interview, self-report, psychometric assessments, teacher questionnaire, medical records, and other official records (Fergusson et al., 1991; Fergusson & Lynskey, 1998). All data gathered as part of the study gained signed consent from the research participants. The research was granted ethics approval by the Canterbury Ethics Committee. The authors have no conflict of interest to declare.

A history of all TBI injury events was constructed using parental/self-report verified *via* hospital records at each follow-up, and an additional review of each hospital file held

for the cohort members (all recorded accidents regardless of type) when they were 25 years of age (McKinlay et al., 2008). Only instances of TBI for which there was a hospital file were included, and each event required a minimum of an overnight stay. Three cases were excluded; two reported TBI events that occurred overseas and one case where no hospital details were available. In these three cases, it was not possible to check details of the injury event.

At the 25-year follow-up participants were asked a series of question relating to TBI using a semi-structured interview format by trained interviewers. Individuals were first asked to recall if, since they had turned 21 years of age (last wave of the cohort when injury information had been collected), they had ever visited a doctor or hospital as a result of an injury to head from a fall, motor vehicle crash, or fight etc. If they answered yes they were asked: (a) did a doctor ever say you had concussion or suspected concussion; (b) were you admitted to hospital for concussion or suspected concussion; (c) did a doctor ever say you had a brain injury; (d) did you have a fracture to your skull. If they answered yes to any of these questions they were asked to specify the following for each incident; age at injury event, nature of accident, nature of injury, hospital attended, nights in hospital (if any).

All cohort members were then asked to think back over their life before turning 21 years of age and remember if they had ever visited a doctor or a hospital as a result of an injury to the head, including when they were a child. If they answered yes they were then asked: (a) did a doctor ever say you had concussion or suspected concussion; (b) were you admitted to hospital for concussion or suspected concussion; (c) did a doctor ever say you had a brain injury; (d) did you ever have a fracture to your skull. If they answered yes to any of these questions they were asked to specify the following for each incident, age at injury event, nature of accident, nature of injury, hospital attended, nights in hospital (if any).

The CHDS also collects information about general health, alcohol use and vehicle collisions, and these records were also scanned to identify individuals who reported an accident but did not identify the injury as a TBI event.

An injury event was considered to be accurate if recall was within 1 year pre/post when the actual TBI event took place. The definition and usage of terms in this questionnaire was guided in part by the Centre's for Disease control 2003 report to Congress on mTBI in the United States (*National Center for Injury Prevention and Control. Report to Congress on Mild Traumatic Brain Injury in the United States: Steps to Prevent a Serious Public Health Problem*, 2003).

Injuries were coded as mild or moderate/severe using information gained from the hospital records. A mild injury was considered to have occurred if the following criteria were not exceeded: (a) LoC <30 min; (b) Glasgow Coma Scale score >12; (c) Post Traumatic Amnesia <12 hr; (d) no subdural hematoma, and (e) hospital records stated a mild TBI had occurred. Injuries exceeding these criteria were considered to be moderate/severe. Using this information, a dichotomous variable was generated (mild = 0 and moderate/severe = 1).

An additional measure of injury severity was generated using a combination of indicators. A score of 0 (absent) or 1 (present) was allocated for each of the following indicators: (1) presence of LoC, (2) recorded LoC >30 min, (3) hospital stay more than 2 days. Resulting "injury severity index" scores ranged from 0 (least severe) to 3 (most severe).

Statistical Analysis

Data were analyzed using descriptive statistics, counts, and percentages with chi square being used to check for significance. Binary logistic regression was used to assess which factors increased the likelihood that a TBI event would be recalled.

RESULTS

In the cohort, there were 101 TBI events that required hospital admission. Nearly 10% of the cohort had been admitted to hospital for a TBI event. Across all age groups 52/101 (51.49%) TBI events were recalled at the 25-year follow-up. Seven additional injuries were recalled but were not specifically identified as TBI due to the multiple sites associated with these injuries. However, when these injuries were included, a total recall of 59/101 (58.42%) was obtained. A Chi square test for independence (with Yates Continuity Correction) indicated no significant association between the sex of the individual and recall for TBI events $\chi^2(1, n = 101) = .701; p = .402; \phi = 0.106$.

There were 59 events where there was a recorded LoC; of these, 40/59 (67.8%) were recalled, and 19/59 (32.2%) were not recalled. There were 42 events where there was no LoC; of these, 19/42 (45.2%) were recalled, and 23/42 (54.8%) were not recalled. A Chi square test for independence (with Yates Continuity Correction) indicated a significant association between the recorded LoC and recall for TBI events $\chi^2(1, n = 101) = 4.253; p = .039; \phi = -0.226$.

Table 1 shows the number of injury events for each of the 5 age bands and level of recall for each group. The total number of TBI events recalled increased with age. Only 25% of TBI events occurring over years 0–4 were recalled at age 25 years compared to 43.8% of those over 5–9 years, 47.4% over 10–14 years and 69.2% and 65.0% for 15–19 years and 20–24 years, respectively. As shown on Table 1, not all injury events were recalled accurately (age at injury within 1 year pre/post actual injury event). For the 15–19 and 20–24 year groups, several injuries recalled were not specifically identified as TBI. In these seven events, multiple injuries had occurred and the TBI was not the focus of medical attention. When these non-specific injuries were included, recall increased to 73.1% and 95% for the 15–19 and 20–24 year age groups (shown in Table 1).

Recall accuracy differed with injury severity. Eleven moderate/severe injury events occurred, 2 over the 10–14 year range, 3 over the 15–19 year age range, and 6 over the 20–24 year age range. All but one of these injury events was recalled.

Table 1. Adult recall of traumatic brain injury and other injury events divided according to age at injury occurrence

Age	Total no. of TBI events	Total no. TBI events recalled (%)	Accurately ^a recalled TBI events (%)	Inaccurately recalled TBI events (%)	Other ^b injuries recalled (%)	Total injuries recalled (%)
0–4 years	20	5/20 (25.0%)	3/20 (15.0%)	2 (10.0%)	0/20 (0.0%)	5/20 (25.0%)
5–9 years	16	7/16 (43.8%)	6/16 (37.5%)	1/16 (6.3%)	0/16 (0.0%)	7/16 (43.8%)
10–14 years	19	9/19 (47.4%)	6/19 (31.6%)	3/19 (15.8%)	0/19 (0.0%)	9/19 (47.4%)
15–19 years	26	18/26 (69.2%)	16/26 (61.5%)	2/26 (7.7%)	1/26 (3.8%)	19/26 (73.1%)
20–24 years	20	13/20 (65.0%)	13/20 (65.0%)	0/20 (0.0%)	6/20 (30.0%)	19/20 (95.0%)

Note. TBI = traumatic brain injury.

^aAn injury event was considered to be accurate if recall was within ± 1 year of when the actual event took place.

^bOccasions where an injury event was correctly recalled but TBI was not identified as the primary injury.

A Chi square test for independence (with Yates Continuity Correction) indicated a significant association between the severity of injury and recall for TBI events χ^2 (1, $n = 101$) = 3.969; $p = .46$; phi = -0.230 .

The majority of the TBI injury events were mild (90), of these 36 were accurately recalled, 41 were not recalled, 6 were recalled as other injuries, and 7 were inaccurately recalled. Inaccurate recall was most frequently related to age at time of injury or errors in time spent in hospital. None of the cohort members reported a moderate/severe injury when a mild injury had been recorded. Twenty-four injuries were reported as occurring for which there was no supporting hospital record, and they had not previously been reported by a parent or the cohort member during earlier follow-ups (false positives). In all cases these injuries had been reported as requiring observation overnight.

Table 2 displays mode of injury for each of the five age bands. As can be seen, falls were most common source of injury in the 0–4 age band (85.0%), whereas motor vehicle accidents was the most common source of injury in the 20–24 year age band (50.0%).

Direct logistic regression was performed to assess the impact of age and “injury severity index” on the likelihood that cohort members would report that they had a history of a TBI event. The model contained two independent variables [Age at injury (whole years), and severity of injury index]. The full model containing both predictors was statistically significant χ^2 (3, $n = 101$) = 30.87; $p < .001$, indicating that it was able to distinguish between respondents who reported and did not report a TBI event. The model as a whole explained between 26.3% (Cox and Snell R square) and

35.5% (Nagelkerke R squared) of the variance in TBI recall and correctly classified 74.3% of events. As shown on Table 3, only age at injury made a unique statistically significant contribution to the model.

DISCUSSION

The aim of this study was to examine the accuracy of adult recall of hospitalized TBI events that had been experienced throughout the lifespan (0–25 years of age). A direct relationship between recall and time post-injury was evident, with decreasing time being associated with increased recall. Only 25% of hospitalized TBI events occurring over years 0–4 were recalled at age 25 years compared to 43.8% of those over 5–9 years, 47.4% over 10–14 years, and 73.1% and 95% for the 15–19 and 20–24 year age groups. We found no significant difference in the recall of TBI events when comparing males and females, but there was an increased likelihood of more severe TBI events being recalled.

Approximately 50% of TBI events experienced by the members of the cohort were recalled. However, it should be noted that the TBI events in the cohort were predominantly mild, with only 10% being classified as moderate/severe. Other factors such as more severe TBI, with visible signs, are likely to be associated with increased recall. For example, in the cohort over 90% of injury events that were moderate/severe were recalled, regardless of the age at which the injury occurred. In light of this finding, it seems likely that life-time screening for TBI among vulnerable populations who are more at risk of severe injury than the general population

Table 2. Mode of injury

Age at injury	Falls	MVA	Sport	Assault	Hit head
0–4 years ($n = 20$)	17/20 (85.0%)	1/20 (5.0%)	0/20 (0.0%)	0/20 (0.0%)	2/20 (10.0%)
5–9 years ($n = 16$)	12/16 (75.0%)	2/16 (12.5%)	1/16 (6.3%)	0/16 (0.0%)	1/16 (6.3%)
10–14 years ($n = 19$)	7/19 (36.8%)	4/19 (21.1%)	6/19 (31.6%)	1/19 (5.3%)	1/19 (5.3%)
15–19 years ($n = 26$)	6/26 (23.1%)	10/26 (38.5%)	4/26 (15.4%)	5/26 (19.2%)	1/26 (3.8%)
20–24 years ($n = 20$)	3/20 (15.0%)	10/20 (50.0%)	1/20 (5.0%)	5/20 (25.0%)	1/20 (5.0%)

Note. MVA = Motor vehicle accident.

Table 3. Logistic regression, predicting the likelihood of an adult report of a traumatic brain injury event

	B	SE	Wald	Df	p-Value	OR	95% CI for OR	
							Lower	Upper
Age	-0.147	0.038	15.264	1	<0.001	0.863	0.802	0.929
Injury severity Index	-0.662	0.395	2.815	1	=0.093	0.516	0.239	1.118
Constant	1.887	0.510	13.715	1	<0.001	6.599		

Note. Df = degrees of freedom; OR = odds ratio; CI = confidence interval.

(Corrigan & Deuschie, 2008; Dams-O'Connor et al., 2014; Kaba, Diamond, Haque, MacDonald, & Venters, 2014; McKinlay, Van Vliet-Ruissen, et al., 2014), would elicit accurate recall of TBI events.

It should be noted, however, that early injury is associated with increased vulnerability in terms of negative outcomes regardless of injury severity (Anderson, Catroppa, Morse, Haritou, & Rosenfeld, 2006; McKinlay & Anderson, 2013). Furthermore, there is increasing evidence that deficits associated with mTBI during childhood are detectable for years following the injury (Alexander, Shuttleworth-Edwards, Kidd, & Malcolm, 2015) and can have a significant impact on adult functioning (Hessen, Nestvold, & Sundet, 2006). Previously, we have reported findings that members of the cohort with childhood mTBI were more likely to have behavior problems in childhood (McKinlay et al., 2002), have mental health problems during adolescence (McKinlay et al., 2009), and engage in increased rates of offending behavior in during their early adult years (McKinlay, Corrigan, et al., 2014). Therefore, identification early mTBI is very relevant, but as shown here, much less likely to be recalled.

How a TBI event was classified during the acute period may explain the false negatives reported by members of the cohort. For example, it is possible that TBI was not identified at the time of injury because this injury was overshadowed by other injuries (fractures, lacerations) that may have been the focus of medical attention (McKinlay et al., 2011).

There were several false positives reported by members of the cohort. Most of these reports were for TBI events that were reported as requiring an overnight stay for observation. Because TBI often results in a period of post-traumatic amnesia and or LoC (Barlow et al., 2010; Mittenberg, Wittner, & Miller, 1997), some of the false positives may have been for TBI where the person was not admitted but spent a period of time in the Emergency Department. However, it could be argued that a false positive does not pose the same difficulties as a false negative, as it flags the possibility of a TBI event.

In the cohort, very few hospitalized TBI events that occurred before age 4 were recalled. Furthermore, details of the injury, such as age, were often not accurate. Our findings are consistent with previous research that has reported a lack of recall for early events as a result of childhood amnesia. Childhood amnesia is defined as a diminished recall for experiences that occur in early life, with increased recall as

the person begins to develop the capacity for individual memory (occurring around 2–4 years of age) (Bruce et al., 2000). The fact that several individuals did recall events that occurred during the time that childhood amnesia would be expected is likely a result of the methods used in this study.

We examined the ability of cohort members to recall any hospitalized TBI event and not just those events for which they held a personal memory (Bruce et al., 2000). Because we only used TBI events that required hospitalization, those details are likely to have been discussed within the family of origin due to distress that can be associated with this level of injury (Youngblut & Brooten, 2008, 2006).

The Christchurch Health and Development Study provided an ideal opportunity to examine the accuracy of adult recall for TBI events that required a period of hospitalization. Information regarding TBI has been collected in the cohort at frequent intervals, from a variety of sources, and repeatedly validated against hospital records. However, there are also several limitations of this method. Cohort members and their parents have been encouraged to recall instances of injuries at multiple time points; this rehearsal of injury events could have increased adult recall. Furthermore, it is possible that TBI was discussed more frequently within the family as a result of being part of a cohort study. Both factors may have resulted in this study representing an overly optimistic estimate of adult recall.

There is increasing evidence that TBI may have long lasting negative effects for some individuals (Catroppa, Godfrey, Rosenfeld, Hearps, & Anderson, 2012; Hessen et al., 2007). These include deficits in attention and concentration, increased substance use/abuse, criminal offending, and mental health problems (Barnfield & Leathem, 1998; Catroppa & Anderson, 2003; Catroppa et al., 2012; Hessen et al., 2007; McKinlay, Corrigan, et al., 2014; McKinlay et al., 2002; McKinlay et al., 2009). Research demonstrates that individuals are disproportionately represented in these at-risk populations (Corrigan & Deuschie, 2008; Corrigan et al., 2007; Williams, Cordan, et al., 2010; Williams, Mewse, et al., 2010). However, the post injury cognitive and impulse control deficits associated with TBI are also likely to make standard interventions less effective and require an emphasis on treatments that accommodate the specific needs of this population. Because of this, there is a need to be able to screen at-risk populations and accurately identify those with a history of TBI (Diamond et al., 2007).

Limited research has been conducted on appropriate screening, and it has been difficult to evaluate the accuracy of individual recall. However, it is clear from this current research that identification of TBI, particularly in at-risk populations, cannot rely solely on individual recall.

It should be acknowledged that TBI alone is unlikely to explain ongoing difficulties, particularly following childhood mTBI. Other factors such as environment, family, and pre-existing problems are likely to contribute to outcomes (Ponsford et al., 1999). On the other hand, TBI should routinely feature as part of a comprehensive clinical evaluation. To ensure that TBI is identified, clinicians should use a comprehensive question regimen, even though it may elicit false positives, and correlate with information from other sources such as parent or significant other recall and hospital records, to verify and enhance the likelihood that TBI is accurately identified. Furthermore, because a comorbid injury may be the focus of attention, additional greater accuracy in screening for TBI events may be obtained by questioning for a lifetime of injuries in general, and filtering out those that are not likely to include injury to the brain.

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