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COUNTING HEADS: ESTIMATING TRAUMATIC BRAIN INJURY IN NEW SOUTH WALES

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Abstract

The public health problem of head injuries contributes to considerable morbidity in the community and is the commonest cause of death in young adult Australians. However, estimating the incidence of head injury has been difficult, and has varied between countries and over time. This paper critically appraises the methodological issues contributing to head injury/brain injury incidence estimates, in particular case definition, differing data sources, and methods of case ascertainment. The most appropriate definition from a methodological service provider perspective is one which clearly distinguishes between potential and actual brain injury. The results from a study which used the most accurate methods have been extrapolated to NSW, and reduce the estimated brain injury incidence in NSW from a reported 392 to 180 per 100,000 incident cases per year. This revised estimate implies that in 1990 there will be about 10,500 new cases of traumatic brain injury, of which an estimated 400 will result in serious physical or mental disability. These estimates were originally calculated to enable the development of an appropriate level of health service provision for brain-injured persons through the NSW Brain Injury Program.

Introduction

Head injury is recognised as a significant medical and public health problem, affecting a young and predominantly male population. In New South Wales (NSW) for example, the overall injury rate in 15-24 year olds is reported to be twice that of the general population, with two to three times as many males as females.[1] The same report concluded that head injury is the commonest cause of death in persons under 40 years of age, and that there were approximately 750 persons permanently disabled from head injury in NSW during 1977.

Morbidity is common after head injury[2-4] with injury severity directly related to degree of disability. Jennett et al.[3] and others have found that approximately two thirds of persons who survive severe head injury have significant residual physical, cognitive or behavioural disability, and become considerably reliant on community services, such as sheltered employment, for the rest of their lives. The financial costs of head injury are enormous. Selecki[1] estimated the direct and indirect costs of neurotrauma in NSW for 1977 to be $949 million.

In response to this problem, NSW, along with other Australian States, has made a commitment to improve the early management[6] and rehabilitation of head injury.[7] Importantly, these programs are consistent with one of the goals of the Better Health Commission: "to reduce preventable death and disability from injury" although their method of achieving it is not through injury reduction (primary prevention), but by better management for the injured victim (secondary and tertiary prevention).[8] Despite the obvious importance of this health issue, detailed information regarding the incidence and outcome of head injury in NSW remains limited. This information is essential for the appropriate planning of health services, from the early treatment provided by emergency and acute hospital services, to later rehabilitation and community services.

This paper aims to review the basic rates of head injury and brain injury frequency and outcome from available data sources in order to estimate public health parameters such as injury and disability rates for NSW. The main emphasis of the paper is on brain injury with major and long-term sequelae. The distinction between potential and actual brain injury and its implications for the interpretation of occurrence data are discussed.

Determining the Incidence of Head Injury

To date, information on the magnitude of this public health problem in Australia has been largely based on a comprehensive survey of neurotrauma which was conducted in NSW, South Australia and the Australian Capital Territory for 1977 and 1978.[1] The survey was population-based and measured the incidence of both hospitalised and fatal, head and spinal cord injury. The study examined many aspects of head injury in

Australia, providing information on the mortality, morbidity and economic costs of neurotrauma in one report, and more recently a detailed analysis of different diagnostic groups.[9-11] Despite the study's broad scope it had several limitations. In particular, assessment of outcome for the total sample was based on the duration of hospitalisation and not on actual patient reviews conducted after the injury, consequently it was not possible to grade level of residual disability for individual cases. Accurate information of this type is of relevance to medical and allied workers concerned to improve outcomes after head injury, and to health planners responsible for the provision of health care services.

Some guidance as to the frequency of different levels of residual disability following head injury was gained from a study of Accident and Emergency attendances at a major metropolitan hospital in Adelaide. In South Australia, Badcock[4] estimated that the annual incidence of moderate disability after head injury was 7/100,000, and the incidence of severe disability was 2/100,000. However these rates are relatively imprecise, being based on only a small number of cases (seventeen cases with moderate disability, and five cases with severe disability) arising in a population base of around 250,000 persons. The implications of Badcock's work will be discussed later.

Incidence rates of head injury from population-based studies conducted in NSW, England and the United States of America are presented in Table 1. These were selected on the basis of the size of the population base (two million or more) and the amount of detail pertaining to injury occurrence and outcome. The rates vary greatly from country to country, with the NSW rate at the higher end of the spectrum. Methodological differences, such as case definitions, the choice of data sources and case finding procedures between these studies make comparisons difficult. These complex methodological issues may invalidate conclusions drawn from a simple comparison of crude rates. A discussion of these issues and an assessment of their impact on estimating incidence rates is presented in the following sections, with specific reference to the NSW data set.

Defining terms: head injury and brain injury

Each study reviewed (Table 1) had a different conceptual or operational definition of head injury, indicating that there is not a single, generally accepted standard definition. However, these definitions usually referred to traumatic brain injury or damage, either actual and/or potential. Field[12], for example, defined head injury as "trauma which carried some risk of damage to the brain". Klauber[13] attempted to identify

TABLE 1

Incidence of head injury from selected population-based studies conducted in England, Australia and The United States of America

Author & Year of Publication	Place of Study	Population size (millions)	Study Period	Rate per 100,000 (per year)	Source of Cases (As defined by Author)
Field (1976)[12]	England & Wales	49	1972	290	Hospital Admissions only
Kalsbeek *et al.* (1980)[30]	United States of America	212	1974	200	Hospital Admissions only
Caveness (1979)[15]	United States of America	214	1976	586	National Health Survey of US households. "Major" injuries, no fatalities.
Selecki *et al.* (1981)[1]	NSW Australia	5	1977	392	All fatalities & hospital admissions
Klauber *et al.* (1981)[13]	San Diego Calif. USA	2	1978	295	All fatalities & hospital admissions, EXCLUDING gunshot wounds
Kraus *et al.* (1984)[14]	San Diego Calif. USA	2	1981	180	All fatalities & hospital admissions, INCLUDING gunshot wounds

"patients whose head injury resulted in skull fracture, unconsciousness, amnesia, neurological deficit or seizure", excluding those with superficial head injuries. Similarly, Selecki[1] defined head trauma as injury to the skull and brain. In contrast Kraus[14] confined his cases to those with documented brain injury, that is "physical damage to, or functional impairment of, the cranial contents from acute mechanical exchange".

The lack of an agreed definition of "head injury" influences the types of injury to be considered, the number of cases identified in a defined population and thus the incidence rate. The most appropriate definition from a methodological and service provider perspective, described by Kraus[14], explicitly distinguished between potential and actual brain injury. This type of definition is particularly useful from a rehabilitation perspective because it clearly identifies cases who are at risk of having residual disabilities.

Data sources and case ascertainment

For each reported study the chosen definitions were operationalised with particular reference to the data sources selected for review. In most studies, head injury cases were enumerated from medically-based record systems such as hospital morbidity data (hospital separations), casualty attendance records and death certificates. Case ascertainment was usually restricted to hospital admissions and death certifications, and can be justified on the grounds that it incorporated a measure of health care utilisation rates, and because of the relationship between injury severity (the need for hospitalisation) and major sequelae.

Household surveys are an important alternative source of information. The American Health Interview Survey regularly obtains data from a national probability sample of households.[15] This survey helps provide information on the number of persons suffering injuries to the brain, face, skull and neck. Survivors of "major" injury to the skull and brain, and those with unspecified open wounds to the head, irrespective of hospitalisation status, were included in the estimate given in Table 1. This type of information was also included in the Australian Health Survey in 1983.[16] The remaining studies presented in Table 1 accessed medically-based record systems and all derived lower rates than the household survey. A review of their case finding procedures follows.

Chronologically, the first medically-based estimate was produced for the year 1972 in England and Wales. For this study, Field[12] utilised hospital morbidity data and general practitioner (GP) consultations. Case identification was based on the International Classification of Diseases 8th Revision (ICD-8)[17] and, for GP practices, on data from the Second National Study of General Practice. The GP cases were not included in the estimate given here because the comparison focuses on hospitalised cases.

In Australia, Selecki[1] utilised coroners' reports and hospital morbidity data, relying on the principal ICD-8 diagnoses to enumerate the head-injured population. He attempted to exclude non-traumatic causes of brain injury (for example subdural haematoma) by using the External Causes codes for specific conditions. Nonetheless, the choice of codes allowed for potential over-estimation by the possible inclusion of non-neurological trauma in the estimate. For example, fractures of the facial bones, and admissions for the late effects of head injury (non-incident cases).

Klauber[13] employed similar methods in San Diego County USA, but excluded several codes used by Selecki after evaluating a sample of medical records to ascertain which codes specified patients with probable skull fractures or intracranial pathology. Penetrating gunshot wounds were excluded from this report. If the NSW data are recalculated based on Klauber's reduced code set (codes N800-1, 803, 804, 850-854), the rate reduces from 392 to 266 new cases per 100,000 persons per year. This is slightly less than the rate reported for San Diego in 1978 and suggests that NSW may not have a higher incidence of head injury when similar categories for data collection are used for both studies.

The National Head and Spinal Cord Injury Survey conducted in the USA was the first study to document the inherent inadequacies of hospital morbidity data and the ICD system in this area.[18] In this survey, possible cases were identified from hospital morbidity data and their medical records were examined for confirmation of head injury. Nearly two thirds of the cases selected by disease codes were subsequently excluded on review of the patient's record. The codes used were similar to Selecki's, however Anderson did not use External codes to exclude cases from the review process. Potential cases were excluded if they had not sustained a traumatic injury, or if inclusion criteria were not met. Cases were included if they experienced one or more of the following events: unconsciousness, fits, headaches, vomiting or a cerebrospinal fluid leak. These findings illustrate that it is necessary to review individual patient records for accurate case ascertainment.

Another approach was employed by Kraus[14], who attempted to locate potential cases of brain injury using Anderson's[18] case-finding methodology with an expanded search of emergency room admission registers and hospital morbidity or coroners' case records. A comprehensive review of hospital records was organised to ensure that diagnostic and incidence criteria were met. Thus, Kraus could be confident of virtually complete case ascertainment of dead and hospitalised cases of brain injury and be able to confirm whether or not they were incident cases. The resulting rate represented a considerable reduction by comparison with Klauber's[13] estimate which was derived three years earlier for the same region.

In addition to case definition, data sources and case-finding procedures may influence estimates of incidence. Medically-based data sources are generally acceptable from an injury severity and service utilisation perspective. Possible cases of brain injury derived from these information systems should be assessed using injury and incidence criteria in order to give an accurate estimate of the incidence of brain injury.

Adjusting Estimates for New South Wales

It follows from the foregoing discussion that through selection of certain definitions and sources of data collection, the existing NSW rates might have been overestimated and, that a recalculation was warranted. The overestimation would be attributable to the inclusion of patients with ICD coded injuries to the face, skull or neck, without assessment of each patient's medical record for evidence of brain injury. It is probable that in the absence of brain injury, many of these cases would have been hospitalised for less than one week and would not have been included in the "permanent residual disability group" described by Selecki.[1]

Several comprehensive population based studies of brain injury from San Diego provide reliable estimates of brain injury occurrence and outcome measures that are not currently available in NSW. However, it may be questioned whether it is reasonable to extrapolate to NSW the rates obtained for San Diego.

Jennett and Teasdale[19] cautioned that the incidence of hospitalised head injury will vary according to the age distribution of the local population and to the admission rates for minor injury. The indications on demographic grounds are not clearcut. The resident population of San Diego has an age and sex distribution typical of the entire USA.[14] While there is a similarity in the age and sex distributions between NSW and San Diego[20], Kraus cautions that "there is a large population of Mexican-American residents and transients. Navy and Marine Corps personnel constitute a substantial part of the population"[14], factors that may influence incidence rates, although transients were excluded from the study. The San Diego rates appear to be influenced by the racial mix and they underscore the rates found in San Diego whites by about 10 per cent.

Nonetheless, a comparison of NSW and San Diego incidence estimates based on hospital morbidity and coroners data presented above would provide similar rates (NSW 1977 266/100,000 versus San Diego 1978 295/100,000). Kraus[14] has suggested that population projections used by Klauber were underestimates which lead to an overestimate of the incidence rate. Kraus has indicated that on 1980 census figures the same number of cases would have given a rate of 250/100,000. Thus this comparison does suggest that the head injury rates in NSW and San Diego are similar, even though demographic differences do exist, and it is therefore reasonable to extrapolate results to NSW. On this basis, the rate of brain injury in NSW is more likely to be between 180 and 200 new cases per 100,000 population per year, than the rate of 392 derived by Selecki.[1]

Brain injury severity and outcome: The San Diego experience

Clearly the work in San Diego County warrants closer examination. San Diego County is located in the southwestern part of California USA and, in 1982, had a resident population of 1.96 million. The county's 1978 and 1981 incidence studies give a detailed account of the occurrence and outcome of brain injury in a defined population. In the 1981 incidence study, Kraus[14,22,23] reported that there were 180 incident cases of brain injury per 100,000 persons and that 160 of these survived to hospital admission. Focusing on the hospitalised population he found that 9 per cent sustained severe injury, 9 per cent a moderate injury, and 82 per cent a minor injury. These rates were reported inclusive of penetrating gun shot wounds (6% of all brain injuries).

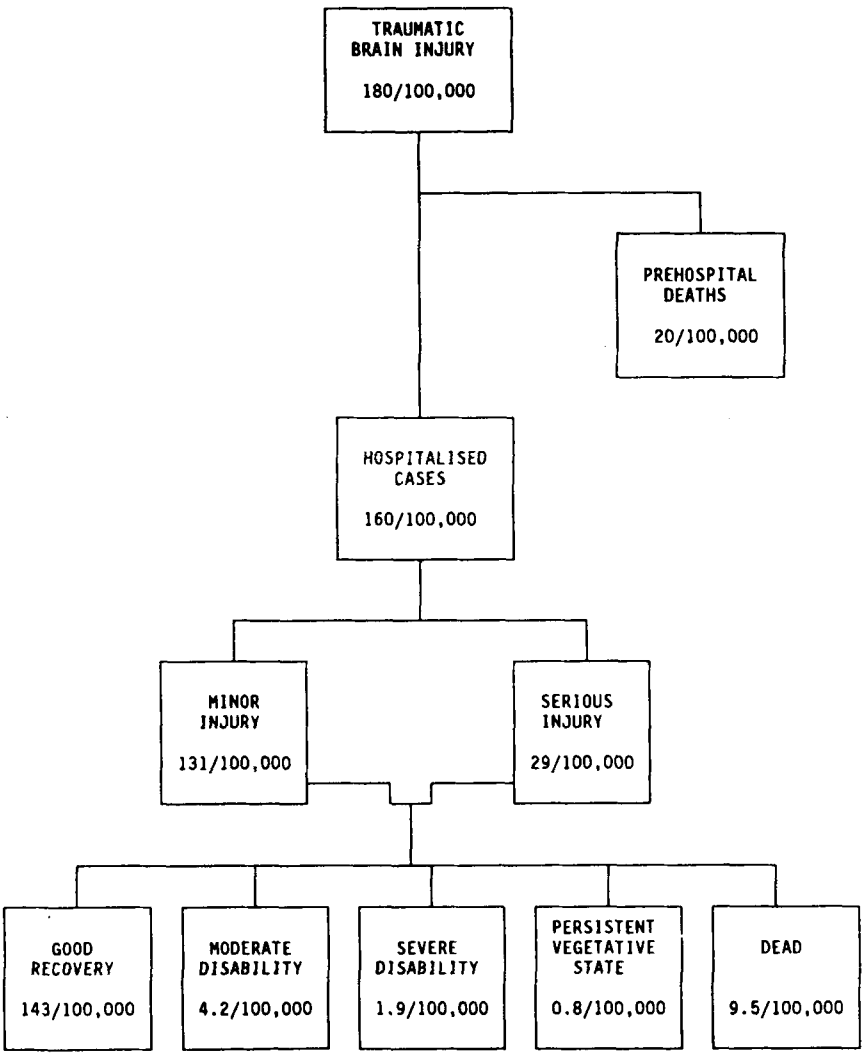
As indicated above, race was shown to affect the incidence of serious brain injury, with whites having a higher rate, such that the rate for all San Diego residents was 93 per cent that of white residents (44/100,000 versus 47/100,000). Rates were also higher for residents from homes with low family income. These analyses were based on 91 per cent of persons with serious brain injury.[22]

Kraus reported a mortality rate of 30 persons per 100,000 population which was 50 per cent

greater than the rate derived from the County Coroner (19.5 persons per 100,000).[24] Kraus extended his work on deaths to include a detailed analysis of cause of death. He found that approximately two thirds of deaths occurred before admission to hospital. Similar finding were obtained from the British and Australian studies.[1,12]

Assessing the primary cause of death, Kraus *et al.*[25] found that in 18 per cent of cases the injuries sustained were unsurvivable. Fifty eight per cent of the remainder died from brain injury, 28 per cent from trauma to extra-cranial sites (including multiple trauma), and 14 per cent died from organ failure (for example, respiratory failure).

Figure 1: Estimated Annual Incidence of Brain Injury in New South Wales, by Severity and Outcome. (Rate expressed as number of cases per 100,000 population)



(Source Kraus et al 1984,1986,1988)[14,22,23]

Kraus[25] also reported that most death and serious disability occurred as the result of moderate or severe head injuries. Twenty-seven per cent of brain trauma in San Diego County was of moderate or greater severity (serious brain injury), an annual incidence of 49 cases per 100,000 persons. The hospital admission rate was lower at 29 cases per 100,000 persons after pre-hospital deaths were taken into account. Sixty-eight per cent of the hospitalised cases survived and one in three had moderate or severe residual disability which is 6.1 disabled survivors per 100,000 persons. Another 0.8 persons per 100,000 remained in a persistent vegetative state. Kraus did not report mild disability rates.

Brain injury in New South Wales

In order to predict the extent of the local brain injury problem, the severity and outcome rates from San Diego have been applied to the projected resident population of NSW for 1990, of approximately 5,850,000.[26] These estimates are based on the assumption that NSW brain injury rates are similar to those in San Diego County. There is at present no alternative strategy to deduce rates because comparable NSW data are not currently available.

From Figure 1, it is estimated that in 1990 10,500 persons will sustain significant brain injury in NSW. An estimated 2,850 persons will be seriously injured (moderate to severe injury) and 1150 will die immediately, although the number of fatalities suggested here is likely to exceed local estimates (from the coroner) by up to one third because of the case-finding procedures used. An estimated 1700 seriously injured persons will survive to enter hospital, along with an estimated 7,900 minor cases. Altogether it is estimated that 9,400 brain injury cases will be admitted to hospital. It is predicted that around 1,150 persons will survive serious head injury in 1990, the majority with some degree of impairment.[27]

An estimated 400 people will suffer major residual disability following brain injury during 1990, 245 cases with moderate disability and 110 with severe problems and it is estimated that 45 will remain in a persistent vegetative state.

The predicted number of deaths and survivors with some degree of impairment or disability is greater, but generally consistent with numbers derived from the 1977 neurotrauma survey in NSW[1], whereas the predicted number of total injuries is substantially less. These findings support the earlier conclusion based on assessment of case-finding procedures, that the overestimation was mainly confined to inclusion of the minor injury rate.

Discussion

There has been around a 40 per cent decline in the fatality rate from the major origin of brain injury – road traffic crashes – since the early 1970s as the result of primary (for example, random breath testing) and secondary (for example, seat belt legislation, helmet wearing) prevention.[28] However, the number of persons killed on NSW roads each year has not fallen as dramatically as the fatality rate because the population has increased in size, and the number of deaths still remains around 1,000 persons. It is relevant that deaths from transport-related incidents in Australia have remained at 40 per cent of all external causes of death for males and fatality rates are rising for females.[29] Thus, despite the decline in road fatality rates, brain injury still poses and will continue to be a significant public health problem, at least in the near future.

New South Wales has responded to this problem by establishing a Brain Injury Program which should have far reaching implications for the rehabilitation and long-term care of the brain-injured in NSW. The data presented in this paper give a comprehensive description of brain injury occurrence and outcome that local data cannot currently provide, and contributed to the estimates needed for the development of the NSW Brain Injury Program in 1986-7. However, in addition to consideration of the validity of the numbers presented in this paper, the precision of estimates must be taken into account when determining service requirements. For example, the moderate disability rate derived from Kraus' study (4.2/100,000) was based on approximately 77 cases.[14] The precision of this estimate (95% confidence intervals) can be calculated using the binomial approximation of the Poisson distribution[31], which in population terms gives a range from 3.3 to 5.1 moderately disabled cases per 100,000 persons. Estimates for uncommon outcomes such as persistent vegetative state are intrinsically less reliable because they are based on small numbers (approximately 15 cases) and therefore must be interpreted more cautiously.

The initial estimates for the Brain Injury Program were produced before the publication of Badcock's work, and they have been re-evaluated in the light of her findings. Badcock's work raised two questions: do the two studies give similar results? and should we recalculate the New South Wales rates based on Badcock's data? As pointed out earlier the estimates from South Australia are less precise than Kraus', for example Badcock's estimate for moderate disability was based on 17 cases – a rate of 7/100,000 and 95 per cent confidence interval of 3.8-10.3/100,000. Clearly,

there is an overlap of confidence intervals between the two studies, although it is less pronounced after adjusting for the predicted under-enumeration of cases (10% missed cases, as suggested by authors, would have increased the case numbers to say 19 - rate = 8/100,000; 95% CI 4.4-11.6/100,000). The severe disability rates differ by only 0.1/100,000 between studies: 1.9/100,000 for Kraus and 2/100,000 from South Australia. Direct comparison of brain injury rates (hospitalised cases and deaths) was not possible because of variance in case definitions. The South Australian investigation identified persons with head injuries using a case definition that did not necessarily distinguish between potential and actual brain injury, except for persons presenting with facial and lower jaw injuries, and found the head injury admission rate to be 250/100,000.[4] Therefore, in answer to the first question, the two studies do give similar results with respect to disability rates.

In response to the second question concerning recalculation of rates, the above comparison indicates that adjustments do not need to be made to the estimates derived for the Brain Injury Program (as presented in this paper). However, the South Australian study provides additional information on patient outcome and health care delivery, which has implications for the Brain Injury Program. Badcock calculated the occurrence of mild disability which at 55/100,000 suggests there will be 3200 persons with mild disability following brain injury during 1990. The South Australian study also documented aspects of health care delivery such as inequality of access to rehabilitation services (females were less likely to be referred for rehabilitation than males) which need to be considered in the implementation of the Brain Injury Program in NSW.

In conclusion, this review examined basic epidemiological data from three countries in order to provide information on the occurrence and outcome of brain injury in NSW. Based on these data, the NSW Brain Injury Program was designed to service the rehabilitation needs of an estimated 10,000 persons who sustain significant brain injury each year. Major rehabilitation facilities are being developed for around 1,000 survivors of serious injury each year, approximately 350 of whom, it is predicted, will be left with moderate to severe physical, behavioural or intellectual disabilities, and approximately 45 who remain in a persistent vegetative state. The service requirements of people with mild disability also need to be considered.

Reliance on these estimates for service development should be seen only as a short-term solution to the data needs of the Brain Injury Program. Access to local information is essential for aetiological research, evaluation and monitoring, the three research components needed for better health.[6] Restrictions on funding for research mean that available data sources will have to be used to provide some of this information. This review suggests that monitoring and some basic aetiological work, such as exploring the urban/rural differential in injury and fatality rates[1,32] could reasonably be achieved through efficient use of hospital morbidity and coronial data. Those States along with NSW that are considering using these data sources for basic information must take into account the specific limitations of the ICD system which have been discussed in this paper, so that accurate occurrence data are reported. In practical terms, the collection process should include case review (on at least a sample of cases) in order to confirm injury and incidence criteria.

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