

1 Introduction

Acquired brain injury (ABI) can result from a number of causes, including head trauma, hypoxia, infection, tumour, substance abuse, degenerative neurological disease and stroke. It can cause physical, cognitive, psychosocial, and sensory impairments, which may lead to restrictions in various areas of life.

ABI is recognised as a disability group in Australia. In 1994 the Commonwealth and State governments agreed on a National Policy on Services for People with Acquired Brain Injury (Department of Human Services and Health 1994). People living with disability resulting from ABI have characteristic support needs that differ from those of people with other types of disability. In particular, because of the acquired nature of ABI and the wide range of impairments that can result, individuals who sustain ABI, and their families and friends, may need to find strategies for coping with changes in lifestyle and expectations.

The impact of ABI at the community level is also quite substantial. ABI, particularly traumatic brain injury, commonly affects people in early adulthood, and survivors may not have substantially reduced life expectancy. Therefore, people with ongoing support needs as a result of ABI commonly live for 20 to 40 years after injury (Jennett et al. 1981). Around Australia there are a number of organisations that represent the interests of people living with ABI.

It is widely recognised that there is a lack of data concerning the prevalence and pattern of disability attributable to ABI. This makes it difficult to assess the level of need for appropriate support services (HICOA 1998; Health Department Victoria et al. 1991). There is also confusion surrounding the terminology used in connection with ABI. Good information on disability at the population level is dependent on consistent definitions that can provide a sound underpinning for statistical data. Common terms also provide a basis for more effective communication, which in turn promotes understanding of people's needs, allowing those needs to be more effectively addressed (Madden & Hogan 1997).

This paper is the third in a series of reports on the definition and prevalence of different disability groups in Australia. The first report in the series focused on intellectual disability (Wen 1997), and the second on physical disability (Wen & Fortune 1999).

Objectives of the report

In this report we set out to critically review:

- definitions of ABI;
- existing estimates of incidence of ABI and prevalence of disability attributable to ABI in Australia and overseas; and
- data sources and approaches to estimating incidence and prevalence.

Newly derived estimates of rates of hospitalisation associated with ABI (treated as indicative of incidence rates) and the prevalence of disability attributable to ABI in Australia are also presented.

Structure of the report

In the remainder of this chapter we review a number of terms commonly used in connection with ABI, some of the issues that face people with ABI and the delimitation of ABI as a disability group.

Chapter 2 provides a review of definitions of ABI used in policy and administrative contexts, and operational definitions used as a basis for data collection and the estimation of incidence and prevalence rates. Approaches to measuring severity of injury and outcome are also discussed.

In Chapter 3 we review international and Australian estimates of incidence and prevalence. The relationship, at a population level, between the epidemiology of brain injury and rates of disability attributable to brain injury is explored.

National estimates of the rates of hospitalisation associated with ABI and the prevalence of disability attributable to ABI, based on the National Hospital Morbidity Database and the 1993 ABS Survey of Disability, Ageing and Carers, are presented in Chapter 4.

1.1 ABI—an overview

Terminology

A number of synonymous and related terms are commonly encountered in the literature on ABI—notably ‘acquired brain damage’, ‘acquired brain injury’, ‘head injury’, and ‘traumatic brain injury’. ‘(Acquired) brain damage’, and ‘(acquired) brain injury’ are usually treated as synonyms, to mean acquired damage to the brain. However, in some cases the word ‘injury’ is taken to imply that the brain has been damaged by some external force. It could be argued, then, that ‘acquired brain damage’ has greater intuitive appeal as a term for describing damage to the brain regardless of cause.

‘Traumatic brain injury’ (TBI) is acquired brain injury caused by a traumatic event—e.g. a blow to the head. TBI is the most prominent subgroup of ABI, and is often the main or sole focus of studies of incidence based on hospital data. Sometimes the term ‘acquired brain injury’ or ‘brain injury’ is used even though the subject of the study is solely TBI.

‘Head injury’ means an injury to the cranium caused by some external force, whether or not brain injury results. ‘Head injury’ and ‘brain injury’ are overlapping classifications in that ‘head injury’ may or may not lead to ‘brain injury’, and ‘brain injury’ may or may not be due to ‘head injury’ (Kraus 1987). Often the term ‘head injury’ is used to mean physical trauma to the head that is likely to be associated with brain injury (e.g. in studies based on hospital data, where the presence of actual brain injury cannot be ascertained). In some discussions a clear distinction is made between ‘head injury’ and ‘brain injury’ (e.g. Health Department Victoria et al. 1991), while in other instances the two terms are treated as synonyms (e.g. Cuff & Donald 1987).

As the term ‘acquired brain injury’ (ABI) seems to be most widely used in the field we will use ABI as an umbrella term throughout this paper to cover all acquired damage to the brain, regardless of cause. The term ‘head injury’ will be used to mean injury to the head where brain damage is likely but cannot be ascertained.

As has been discussed in a previous paper in this series (Wen & Fortune 1999), terminology used in relation to disability generally is in a transitional phase. In this paper ‘impairment’ will be used to mean ‘a loss or abnormality of body structure or of a physiological or psychological function’, as it is defined in the draft ICIDH–2 (see Section 2.3). ‘Disability’ will be used as an umbrella term meaning negative experience in any one or more of the draft ICIDH–2 dimensions—i.e. an impairment, activity limitation or participation restriction. (See Appendix 1 for definitions of terms used frequently throughout this paper.)

Damage to the brain

Damage to the structure or function of the brain can lead to a wide range of impairments of varying degrees of severity. Acquired brain injury may result from many different causes, including trauma, such as a blow to the head or a sudden arrest of movement ('acceleration/deceleration' injury), disruption to the supply of oxygen to the brain, stroke, tumours, infection (e.g. meningitis), poisoning and substance abuse, and degenerative neurological diseases.

The nature of damage and parts of the brain affected can vary with the cause. In some cases damage is diffuse and widespread. For instance, in 'acceleration/deceleration' injuries, such as those often sustained in motor vehicle accidents, nerve fibres and blood vessels throughout the brain can be torn by shearing stresses. Prolonged alcohol abuse tends to cause diffuse neuronal damage. In other cases damage is focal. In traumatic brain injury specific parts of the brain may be impacted against the skull and bruised or torn. Stroke also tends to cause localised damage in the brain (Jennett et al. 1981).

In recent decades the development of technologies such as computerised tomography (CT) and magnetic resonance imaging (MRI) have provided new insights into brain injury. These technologies are now used routinely as diagnostic tools and have confirmed that there is often structural brain damage even in people whose injuries appear to be mild (Jenkins et al. 1986). In some incidence studies results of CT scan and MRI are used to confirm cases of brain injury or to assess severity (e.g. Kraus et al. 1984; Servadei et al. 1988). The ability to detect injury to the brain that might previously have been overlooked means that more people are likely to receive appropriate post-injury support.

The nature and severity of damage to the brain, along with other medical, social and personal factors, influence the nature and severity of resulting disability. The brain is of central importance in every aspect of physical, cognitive, sensory, behavioural and social functioning. While people with only one type of impairment (e.g. mental or physical) may be able to develop compensatory adaptations, people with more than one type of impairment are less able to do this (Jennett & Bond 1975). The wide range of types of disability that can result from ABI means that people with ABI have very diverse support needs.

Disabilities and service needs

The focus of this paper is on the incidence and prevalence of ABI. However, in order to provide a context for this focus it is necessary to outline briefly some aspects of the disabilities experienced by people with ABI and issues that face them in the community.

The effects of acquired brain injury are complex, and individuals are affected differently. Brain injury may lead to physical, sensory, cognitive and psychosocial/emotional disabilities, often in combination (Kendall 1991). A follow-up study of people with traumatic brain injury found that the most frequently reported ongoing problems, several years post-injury, were poor memory, irritability, loss of temper, headaches, and difficulty concentrating (Tennant et al. 1995). ABI is sometimes referred to as the 'hidden' disability, because individuals can appear 'normal' but experience cognitive or emotional disabilities. Emotional and social difficulties, including aggression, depression, mood swings and disinhibition, can be particularly challenging for individuals and their families—close relationships may be affected by changes in personality and behaviour caused by the brain injury.

The ultimate goal for a person with ABI is often to be a participating and valued member of their family and community. However, re-entering the community can be very challenging. The person may find themselves disconnected from their social circle and unable to return to

work. Negative community attitudes and a widespread lack of understanding of ABI increase the difficulties they face.

People with ABI may need support to help them build relationships and establish social networks, achieve independence and autonomy in day-to-day life, access community resources and services, build confidence and self-esteem, develop skills, and find work. Successful community integration is likely to depend on long-term access to appropriate specialist and generic services.

In recent years specialised brain injury services have been established around Australia in response to community demand and in recognition of the unique needs of people with ABI. A study conducted in 1995, that looked at barriers preventing people with ABI accessing appropriate services, identified 48 organisations across Australia specifically funded to provide services for people with brain injury (Ramsey & Hilson 1995). However, a literature review conducted as part of that study revealed that people with ABI generally had insufficient access to services in a range of areas, including rehabilitation, accommodation and respite. Factors that made it difficult for people with ABI to access services included: absence of appropriate services; means testing, which may exclude people eligible for a compensation payment in respect of their brain injury; lack of funding and resources; lack of awareness of appropriate services; inaccessibility, due to physical factors or other factors including communication barriers; and lack of understanding of the needs of people with ABI on the part of service staff (Ramsey & Hilson 1995).

Views expressed in an ABI consumer focus group, concerning changes being made to employment assistance under Centrelink, included that service staff need to have an understanding of the differences between ABI and other disabilities. A poor understanding of ABI may reduce the likelihood of the person being given a suitable work placement and receiving appropriate support. There was also a concern that assessment instruments, such as work ability tables, designed for people with other types of disability are unlikely to pick up the kind of difficulties experienced by people with ABI (Headway Victoria 1998).

1.2 ABI as a disability group

Disabilities are often categorised into 'disability groups'. The concept of 'disability group' was first formally introduced in the Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS) Data Guide for the 1997 collection. The Data Guide defines disability group as 'a broad categorisation of disabilities in terms of the underlying impairment, condition or cause' (AIHW 1999a). From a data perspective, it is necessary to clearly delineate a disability group before questions of incidence and prevalence can sensibly be discussed in relation to that group.

Groupings reflect common usage in the disability field, rather than a universally agreed classification of disabilities. Existing 'groups' in Australia (e.g. intellectual, physical and ABI) tend to include people with a disability who are considered—by themselves, society, and/or service providers—to have similar characteristics and related needs, often arising from a similar cause, impairment or disabling condition (unpublished agenda paper of CSDA MDS annual network meeting 1998).

ABI as a disability group is not easily defined. As discussed above, ABI may result from a variety of causes and people with ABI may experience a wide range of impairments and activity limitations. Nonetheless, ABI is recognised as a disability group in the field because people living with ABI maintain that their needs and experiences are different from those of people living with other types of disability (e.g. physical or intellectual) (HICOA 1998).

In the USA traumatic brain injury is singled out in legislation as a disability group worthy of special recognition. In the explanatory notes for the Traumatic Brain Injury Act (1996, USA)

it is stated that 'because of the serious consequences of TBI and the failure of human services systems and educational programs to meet their needs properly, people with TBI want to be identified as people with brain injuries, not to be labelled as having some other disability. This is extremely important if appropriate services are to be developed and targeted and prevention efforts are to be conducted'. The Individuals with Disabilities Education Act defines the term 'child with a disability' as a child with any of a list of stated impairments and disabilities including 'traumatic brain injury' (20 USCA § 1400 (West Supp. 1998)).

In Australia in 1994 the National Policy on Services for People with Acquired Brain Injury was developed as 'a statement by Commonwealth, State and Territory Governments on the future direction of service provision and support for people with Acquired Brain Injury' in response to 'growing concern about the impact of ABI in the community' and 'issues raised by people with ABI and their families and carers, the organisations which represent them, and government and non-government service agencies' (Department of Human Services and Health 1994). The scope of ABI as laid out in the policy encompasses ABI resulting from trauma, alcohol abuse, hypoxia, tumour, stroke and infection.

However, the limits of ABI as a disability group are not clearly defined, and there is scope for overlap with other disability groups. For instance, disability resulting from some degenerative neurological diseases may be regarded as ABI or as neurological disability (often treated as a subgroup within physical disability—Wen & Fortune 1999). Decisions on this point, for the purpose of service delivery, may need to be made on a case by case basis (Geraldine Jones, Brain Injuries Options Coordination, pers. comm.).

People with brain injury acquired before, during or shortly after birth are not usually included within the group by service providers or representative organisations in Australia (Geraldine Jones, Fay Rice, pers. comm.)—this is perhaps because change in life circumstances and identity are important characteristics of ABI. People with brain injury from birth are more likely to be included in the intellectual disability group. However, common definitions of intellectual disability—which usually involve low intellectual functioning and onset before age 18—may encompass many people with brain injury acquired during childhood or teenage years (see Wen 1997).