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Towards a disability-oriented epidemiology of traumatic brain injury

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Summary

The aim of this study was to investigate the value of using a disability-oriented approach to the epidemiology of traumatic brain injury (TBI) in order to improve health administration by preventing long-term sequelae. The epidemiology of disease was established by a registration system of inpatients which covers more than 99% of all hospital admissions in The Netherlands. Some international differences and national trends are discussed. The disability-related epidemiology was investigated by means of structured interviews, 3-7 years after the injury, in a clustered sample of 51 patients with major TBI according to the ICD-9-CM. The survey included evaluation scales such as the Sickness Impact Profile, the Barthel Index, and a Disability Rating Questionnaire. Concerning the disease-related epidemiological data, the overwhelming majority of all TBI patients went home, which suggests good recovery. Nevertheless, the disability-oriented research revealed long-term situational, cognitive and behavioural disabilities in at least 67% of the major-TBI population, whereas only 10% received any rehabilitation services at all after the acute-care period. It is concluded that preventive measures and a comprehensive service for brain injury survivors should be based both on disease and disability-oriented data.

Introduction

About 30 years ago epidemiology was described as the Cinderella of the medical sciences.¹ It is questionable whether this qualification has ever changed with respect to traumatic brain injury (TBI). The aim of epidemiological studies is to describe the frequency and patterns of distribution of disease, as well as to identify aetiological factors in the pathogenesis in order to generate data relevant for outlining possible approaches to prevention and health administration.²

For TBI an epidemiology of disease is not sufficient to fulfil the needs of health administration. Although incidence

rates and specific information on age, gender, cause, circumstances, and time of onset of TBI are important for the planning of emergency medical care units and acute-care facilities, not to mention the planning and evaluation of primary preventive measures, these figures are considerably less useful in planning and evaluating rehabilitation services and long-term care facilities for brain-injured patients. These services are in fact disability-oriented rather than disease-oriented, with disability being defined as 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being' (ref. 3, p. 143). Since TBI is nothing more than a general term connected with a variety of disabilities, no straightforward relation exists between the trauma and these disabilities. Therefore, long-term outcome cannot be predicted solely on the basis of injury characteristics, but should also be based on patient-related variables such as age, pre-trauma status, pre-trauma coping styles, cognitive deficits, self-presentation, acceptance and family support system. In addition the final outcome also depends on health administration-related variables, such as the availability of services and professional staff. Further, to answer questions such as 'How many persons are disabled by TBI in terms of neurobehavioural problems or capacities to work?', a disability-oriented epidemiological approach is needed. Such an approach is essential for the planning and evaluation of brain injury rehabilitation services and long-term care.

There is also a financial consideration which argues in favour of using a disability-oriented approach. Indeed, to calculate the consequences of the disease in economical terms, information is needed which reflects the overall cost outcome. Such overall costs include not only the *direct* costs of transportation, hospital admission, initial therapy, rehabilitation services, long-term facilities, home care, and social benefits, but also the *indirect* costs which are related to a loss of market earnings because of unemployment.⁴ Direct costs are established by disease as well as disability-associated measures. Indirect costs are related to disability-oriented data. Comprehensive cost estimations for TBI

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should therefore be based both on disease- and disability-oriented epidemiological data.

Although many studies have appeared on the incidence of TBI (e.g. refs. 5-9), and on the long-term consequences of brain injury (e.g. refs. 10 and 11), most of these studies are biased to a lesser or greater extent by serious patient-selection problems.^{12,13} Foremost are the inconsistencies in the definition of brain injury. Until now there exists no unambiguous definition, and a uniformly accepted diagnostic standard is lacking. A traumatic *brain* injury may be defined as a condition of impaired functioning of the *brain*, as a result of a violent blow or impact.¹⁴ Yet many studies rely on hospital discharge codes including *head* injury or fractures of the skull. This, obviously, may lead to an over-estimation of *brain* injury. However, an incomplete recording of clinical observations or discharge codes, on the other hand, may lead to an under-estimation. Even though symptoms may be recognized as the consequences of brain injury, patients in a non-neurological ward are often registered only by a diagnosis in the domain of orthopaedics or internal medicine. Furthermore, too many different search strategies exist to expect uniform incidence figures. For example, diagnoses are made at different times and places (at the scene of the injury, in the emergency department, at discharge), different methods of case ascertainment are used (self-reporting to an interviewer, reporting by a physician, searching for ICD-9 codes as coded by medical record personnel), and different patient groups are included (inpatients and/or outpatients). As a consequence, inferences based on these studies may be unreliable. Studies focused on the incidence rates of TBI *combined* with subsequent incidence rates of the consequences of TBI in terms of disabilities are extremely rare. This kind of information, however, is a prerequisite for the effective planning of rehabilitation services. The purpose of this paper is to discuss the increase in value of such a disability-oriented epidemiology of TBI above epidemiological studies of TBI based solely on the disease characteristics.

Method

PROCEDURE

In The Netherlands, patients admitted to general and university hospitals with the diagnosis 'traumatic brain injury' are registered according to the WHO's *Manual of the International Statistical Classification of Diseases, Injuries, and Causes of Death*, Ninth Revision (ICD-9-CM). Principal as well as sub-diagnoses are encoded. These data are centrally stored by the 'Stichting Informatiecentrum voor de Gezondheidszorg' (SIG). Upon request the SIG provides users with diagnosis-specific information. This registration system covers more than 99% of the nation's hospital

admissions, including 24-hour observations. It contains information about sex, age, mean admission time, and direction of discharge, which could be home, rehabilitation centre, nursing home, psychiatric hospital, or other institutions.¹⁵

To ensure that a traumatic *brain* injury had been diagnosed, only categories containing information of concussion or contusion were included in this study. The following codes were selected to provide disease-oriented epidemiological information: 850.0-850.9 (minor traumatic brain injuries, MI-TBI) and 800.1; 800.6; 801.1; 801.6; 803.1; 803.6; 804.1; 804.6; 851.0-851.9 (major traumatic brain injuries, MA-TBI). Primary and secondary diagnoses are encoded. Van Balen^{16,17} showed that, in order to present an epidemiology of disabilities, data concerning the everyday life of patients are needed.

Although it is recognized that the indirect effects of haemorrhages, haematoma, oedema, and ensuing physiological processes may be as destructive as the immediate effects of the impact, categories merely indicating skull fractures (e.g. 800.0, 801.0 and 803.0), or subarachnoidal, subdural, and epidural haemorrhages (e.g. 800.2, 800.3, and 800.7) have been excluded from the study. Though the exclusion of these and other categories may seem too conservative, the inclusion of injury-related diagnoses that do not refer directly and unambiguously to brain injury may lead to an over-estimation by as much as a factor of ten.¹⁸

Using cluster sampling based on geographical area (living in the 'Greater Nijmegen area' at the time of the accident), age (between 14 and 30 years at the time of the accident), and year of hospital discharge (between 1981 and 1987), it was estimated that 125 major (MA) TBI patients and 375 minor (MI) TBI patients would be admitted to the regional university hospital. Hospital discharge administration revealed 124 MA-TBI patients ranging in age from 15 to 30 years, which is very close to the expected number. This underscores the policy of referring the more severely injured TBI patients directly to the university hospital. As only 38 MI-TBI patients were registered, MI-TBI patients have been excluded from the disability-oriented part of this study. Several factors may account for the remarkably low score for this category. In the first instance many patients suffering a minor brain injury are attended to by their general practitioner. Eventually, they are admitted to one of the three general hospitals in the Greater Nijmegen area (population 271 800). Furthermore, the university hospital's policy does not allow the admittance of many 24-hour observation patients with MI-TBI as the hospital provides a specialized neurotraumatological unit with a high bed-occupation percentage.

The data were collected by means of a series of structured

interviews with TBI patients and family members; these took place at home, 3-7 years after the injury.

Only 15-30 year-olds were included in the present study, for three major reasons: (1) this age range encompasses 30-35% of all MA-TBI patients (see also Table 2); (2) in this age range many important decisions have to be made concerning education, partner relationship, work, and housing; and (3) this group seems to generate a substantial part of the *indirect* costs, those costs related to a loss of market earnings because of unemployment. In addition, some services, e.g. special schools for learning-disabled children, are not available to individuals in this age category.

Family members were included in the study for several reasons, e.g. very severely brain-damaged patients may be unable to participate in an interview as a result of their neurobehavioural impairments. In addition, interviewing the patient as well as a family member makes it possible to compare different views on long-term sequelae. This is important, as unawareness of deficits is a characteristic of a significant number of brain-damaged patients, even when these deficits have a clear negative effect on behaviour.¹⁹ Other advantages have been discussed by Brooks,²⁰ who concluded that failing to include family members will result in an inadequate analysis of the functional consequences of brain damage.

ASSESSMENT INSTRUMENTS

A structured interview has been developed that is based on clinical experience, standardized questionnaires, and items mentioned in the literature. All participants were interviewed at home. The average interview time was 2 hours (range 45 minutes to 6 hours) and included evaluation scales such as the Barthel Activities of Daily Living Index,²¹ the Sickness Impact Profile,^{22,23} the Employability Rating Scale,²⁴ and the Wimbledon Self-Report Scale.²⁵

These instruments were chosen because they cover the most important domains of daily living, and because their relevance has been shown in research with brain-injured populations. A description of these assessment instruments follows.

Functional ability has been measured by means of the Barthel Activity of Daily Living (ADL)-Index.²¹ This scale produces a score between 0 and 20. A score of 0 indicates total dependence, whereas a score of 20 implies functional independence, but not necessarily normality. The following items are covered: bowels, bladder, grooming, toilet use, feeding, transfer (bed-chair), walking, dressing, stairs, and bathing. The validity of this index has been established in several studies and is related, as expected, to motor loss.²⁶

Employment status was measured using the Employability Rating Scale.²⁴ This rating scale has been specifically

developed for use as an instrument for assessing employment status.

The Sickness Impact Profile (SIP)^{22,23,27} is one of the very few standardized measures of day-to-day functioning that are known to be sensitive to alterations in the real-life daily activities of brain-injured patients. The SIP is a behaviour-based measure of health status composed of 136 statements about health-related dysfunction. Dysfunction is defined as the 'modification or impairment in degree or manner of carrying on an activity, cessation of an activity, or initiation of a new activity that interferes with or substitutes for a usual activity'.²² Each of the SIP statements describes a behaviour. The subjects orally confirm each statement presented if it describes their current behaviour, and if it is related to their actual state of health. The items are grouped into 12 categories or areas of living: sleep and rest, emotional behaviour, body care and movement, home management, mobility, social interaction, ambulation, alertness behaviour, communication, recreation and pastimes, eating, and work.

To measure emotional and mood appraisal the Wimbledon Self-Report Scale (WSRS) was used.²⁵ The purpose of this scale is to appraise the emotional state, and to detect mood disturbances in the general population and in people with neurological or major physical illness. The WSRS comprises 30 adjectives and phrases describing 24 unpleasant feelings (e.g. 'worthless', 'as if my life has been ruined') and six pleasant ones (e.g. 'confident', 'in good spirits'). The subject is required to rate, using a four-point scale, each orally and written presented item for its pervasiveness in the past few weeks. High scores indicate pervasive unpleasant feelings.

Disabilities were assessed by means of an orally presented Disability Rating Questionnaire (DRQ), consisting of 51 items and covering a wide range of symptoms, physical (e.g. paresis, headache, vertigo) as well as behavioural (e.g. inability to do two or more things simultaneously, reduced social skills, reduced behavioural memory). Subjects were asked to judge their present state in relation to their functioning before the injury. The questions were framed in simple language, and often examples were used to ensure that subjects understood what the interviewer was asking. If items such as lack of initiative were indicated by the subject, the investigator scored the item only if it was experienced as a consequence of the brain damage.

Other topics covered by the interview were experienced failures of the health-care system, use of external aid devices, changes in housing and relations, global self-evaluation, and practical independence.

SUBJECTS

The 124 patients mentioned above were all admitted to the University Hospital Nijmegen with a diagnosis of MA-TBI.

Table 1. Registered minor (MI) and major (MA) traumatic brain-injured (TBI) inpatients in The Netherlands from 1982 to 1986, and 1990, and 1991.

Diagnoses	Year						
	1982	1983	1984	1985	1986	1990	1991
MI-TBI	13 272	12 676	11 657	11 169	10 350	9 193	8 344
MA-TBI	4 987	4 938	4 553	4 573	4 208	3 535	3 471
Total	18 259	17 614	16 210	15 742	14 558	12 728	11 815

Source: SIG.

Of these, 72% were admitted after a traffic accident. Three patients died during hospital admission. A random group of 61 persons out of 121 were mailed a request to participate. Fifty-one (84%) patients or family members responded positively, four patients and three family members refused to participate. The new addresses of three patients could not be found.

A patient population of 28 men and 23 women participated in the study. The interviewed patients ($n = 49$) ranged in age from 21 to 34 years (mean = $26;3 \pm 4;0$ years). The family members interviewed ($n = 48$) included: both parents (50%), mother (36%), sibling (9%), and spouse (5%).

Results

The disability-oriented results will be presented after the disease-oriented data. The latter include incidence and mortality rates, sex and age distribution, mean admission time, and direction of discharge. In addition, attention is given to some trends of the past decade which further specify the clinical population. Although disability-oriented data are presented only for MA-TBI, the epidemiology of disease includes MI as well as MA-TBI to provide a more complete picture. It should be remembered that the data cover inpatients only.

EPIDEMIOLOGY OF DISEASE

Table 1 shows incidence rates of registered MI and MA-TBI inpatients in the years 1982–1986. These are the years in which the subjects participating in the interview were admitted to hospital. In addition, the incidence of 1990 and 1991 is presented to provide a comparison for some trends. The Dutch population increased from 14 395 000 in 1984 to almost 15 000 000 inhabitants in 1991. In the same period (1984–1991) a dramatic decline of the absolute number of inpatients can be observed (see Table 1). Whereas the incidence rates per 100 000 inhabitants in 1984 for MI-TBI were 81.0 and 31.6 for MA-TBI, in 1991 these rates dropped to 55.6 and 23.1 respectively. During the 1980s a decrease in overall TBI-incidence rate is found from 112.6 in 1984 to

78.8 in 1991 (minus 29%). In the same period the mortality rate dropped from 2.6/100 000 to 1.5/100 000 (minus 42%).

The overall ratio of men and women with TBI has remained stable in the past decade, viz 62% to 38% ($\pm 1\%$). In the age cohort of 15–30-year-olds this sex ratio is slightly different, but again very stable: 67% to 33% ($\pm 1\%$).

In the past decade, approximately 25% of the TBI patients were younger than 15 years old, approximately 35% between 14 and 30, with 40% being 30 years old or older. Table 2 presents detailed information. As these data show, increases can be observed in the age cohort 30+, for MI-TBI patients from 36% in 1982 to 41% in 1991 and for MA-TBI patients from 37% to 47%.

In agreement with other studies,¹² the statistical risk of TBI is highest for individuals older than 85, and second highest for the ages between 14 and 25. The risk drops dramatically and is lowest in the decade after the age of 34, but it shows a progressive increase for the elderly.²⁸ For individuals older than 85 the (statistical) risk is about three times greater than for the age group between 35 and 44 years.

Notwithstanding the reduction of incidence rates during the last decade, in 1991 the TBI population is still responsible for 0.8% of all patients admitted to general and university hospitals (1.1% in 1982). In terms of mean admission time the past decade showed a gradual, but significant, decrease for MI-TBI as well as MA-TBI (40% and 23%, respectively).

Table 2. Percentages of the incidence of minor (MI) and major (MA) traumatic brain-injured (TBI) in different age categories for 1982 and 1991.

Diagnoses	Age (years)	Year	
		1982	1991
MI-TBI	<14	26	25
	15–29	38	34
	30+	36	41
MA-TBI	<14	28	23
	15–29	35	30
	30+	37	47

Source: SIG

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Table 3. Mean admission time in days for minor and major traumatic brain-injured patients without skull fractures.

Diagnoses	Year						
	1982	1983	1984	1985	1986	1990	1991
MI-TBI	10.1	9.5	9.0	8.2	7.8	6.7	6.0
MA-TBI	18.6	17.7	18.0	17.1	16.7	16.6	14.4

Source: SIG.

This seems to reflect the overall reduction in the number of hospital beds during the past decade and the policy of Dutch hospitals to discharge patients as soon as possible. Table 3 presents an overview.

Concerning the direction of discharge (home, rehabilitation centre, psychiatric hospital, etc), little information is available from the literature. In the nationwide registration system these data are registered in terms of seven categories: home, home (contrary to the advice of the physician), other hospital, rehabilitation centre, psychiatric institution, nursing home, and other institution. The overwhelming majority of discharged brain-injured patients went home (MI-TBI patients $98 \pm 1\%$, MA-TBI patients $91 \pm 1\%$), of which about 1% were contrary to the advice of the physician. Of the MI- and MA-TBI patients, 1% and 6%, respectively, went to another hospital. This is probably explained by the fact that some of those admitted to a regional hospital had been transferred to a neuro-traumatology unit of a university hospital. The overall picture shows that only a very small percentage receives subsequent rehabilitation services (MI-TBI patients $< 1\%$, MA-TBI patients *circa* 2%) or nursing-home facilities (MI-TBI patients $< 1\%$, MA-TBI patients *circa* 2%). Although no nationwide data are available concerning the percentage of patients who were discharged to the home situation but later were sent to rehabilitation, a somewhat higher percentage is plausible: in this sample 10% of the MA-TBI patients received any rehabilitation services. Less than 1% of the TBI patients received other kinds of institutionalized health services.

EPIDEMIOLOGY OF DISABILITY

Disabilities may arise as a direct consequence of impairment, or as a response by the individual to an impairment. As defined in the *International Classification of Impairments, Disabilities and Handicaps*,³ an impairment is 'any loss or abnormality of psychological, physiological, or anatomical structure or function' (p. 47). As such, disabilities reflect disturbances at the level of the person. In this classification nine main categories of disabilities have been formulated and labelled as 'behaviour', 'communication',

'personal care', 'locomotor', 'body disposition', 'dexterity', 'situational', 'particular skill' and 'other activity restrictions'. As the employed measurements do not allow a seamless fit to the above-mentioned WHO categories, the disability categories in this study are adapted slightly, and are presented in Table 4.

Although family members consistently indicate a higher percentage of the MA-TBI patients as being affected by long-term disabilities (see Table 4), these differences are not significant. Furthermore, the percentages of the different disability categories show the same rank order for patients and family members, with situational disabilities being highest, followed by cognitive, behavioural/emotional, social, locomotor, and personal care disabilities. As will be presented below, an item analysis reveals the differences at a more detailed level.

Situational disabilities incorporate dependence and endurance disabilities as well as environmental disabilities relating to tolerance of noise, light, and stress. They are reflected by symptoms such as headache, tiredness, and hypersensitivity to everyday visual and auditory stimuli or work stress. With reference to Table 4, 67% of the MA-TBI patients indicated at least one of these manifestations as a disability in daily life. Although family members tended to mark more situational disabilities (75%), only the increased need for sleep showed a significant difference between the two groups (NPAR M-W test, $p < 0.05$). Headache is the symptom most frequently mentioned by TBI patients (41%) and family members (45%).

Cognitive disabilities include disabilities as a result of impairments in mental speed, orientation, perception, concentration, language, memory, and executive functions. Table 4 shows that 55% of TBI patients and 65% of family members indicate at least one cognitive disability. In agreement with other studies (e.g. ref. 10), disturbances in everyday memory functioning are mentioned most frequently by TBI patients as well as family members (43% and 53%, respectively). Other disturbances often indicated as disabilities are mental slowness, attentional deficits, difficulties relating to orientation in time and space, and the inability to perform two or more activities simultaneously.

Table 4. Percentages of major traumatic brain-injured (MA-TBI) with long-term disabilities indicated by MA-TBI and family members (FM).

Disabilities	Group		Assessment instruments
	MA-TBI (n = 49)	FM (n = 48)	
Situational	67	75	DRQ, SIP _{sr}
Cognitive	55	65	DRQ, SIP _{ab, c}
Behavioural/emotional	45	56	DRQ, SIP _{eb, wsrs}
Social	25	38	DRQ, SIP _{si}
Locomotor	10	12	SIP _{a, m}
Personal care	0	2	Barthel, SIP _{bcm, e}

DRQ = Disability Rating Questionnaire; SIP = Sickness Impact Profile, sr = sleep/rest, ab = alertness behaviour, c = communication, eb = emotional behaviour, si = social interaction, m = mobility, a = ambulation, bcm = body care and movement, e = eating; WSRS = Wimbledon Self-Report Scale

Behavioural and emotional disabilities refer to an individual's awareness of his/her conduct and the appropriateness of that conduct, both in everyday activities and towards others. Behavioural and emotional disabilities may be conceived to be predominantly the result of the interaction between primary disorders, including organic-related impairment of emotion, affect, and mood, and secondary disturbances related to, e.g., acceptance, role changes, and reactions of significant others. As shown in Table 4, 45% of TBI patients and 56% of family members mark at least one behavioural or emotional disability. More specifically, irritability is most frequently mentioned, followed by depression, judgement disorders, and aggression. Childish behaviour, irritability and inappropriate social behaviour are significantly more often indicated by family members than by TBI patients (NPAR M-W test, $p < 0.05$).

The detection of mood disturbance was determined by the presence of adverse emotions and the absence of positive feelings. The self-ratings obtained by using the WSRS showed that 10% of TBI patients and 15% of family members' ratings were marked as a 'case', i.e. a clinically significant mood disturbance.²⁵ Items most often mentioned (by TBI patients as well as family members) were tension, lack of relaxation, and lack of confidence. With the exception of feelings of guilt, regret, annoyance, lack of confidence, and lack of good spirits, almost all items from the WSRS were rated higher by family members than by TBI patients. For desperate and panicky feelings this difference is significant (NPAR M-W test, $p < 0.05$).

Disabilities concerning social behaviour include diminished social skills, antisocial behaviour, and reduced social activities. Table 4 gives an overview (TBI patients 25%, family members 38%). The item most frequently indicated by TBI patients is reduced social activities, whereas family members often marked diminished social skills and irritability against others as well.

Locomotor disabilities were mentioned more often than personal-care disabilities (see Table 4). These disabilities related almost exclusively to ambulation. Subsequent exploration of the data revealed that, although all respondents were able to walk or to climb stairs, some people had more endurance limitations or speed limitations than before, particularly with climbing stairs (8%). Furthermore, no-one reported transfer disabilities. One person (2%) experienced difficulties with biking, and 12% were unable to drive a car because of TBI sequelae.

Finally, *personal-care disabilities* refer to 'an individual's ability to look after himself in regard to basic physiological activities, such as excretion and feeding, and to care for himself, such as with hygiene and dressing' (ref. 3, p. 157). As can be concluded from Table 4, only one person (2%) suffered from personal-care disabilities. However, one should realize that the data presented concerning personal-care disabilities were primarily related to the level of independence. Thus, although a TBI patient may be fully independent in terms of personal care as measured by the Barthel Index, that person still may need more time than before to execute activities such as bathing or getting dressed (which in fact was reported by some).

In summary, as an item analysis within the different disability categories showed, significantly more family members indicated increased need for sleep, irritability, childish and inappropriate social behaviour, as well as more desperate and panicky feelings. From this it can be concluded that the discrepancies in judgement of long-term sequelae between family members and TBI patients are mostly in the behavioural and emotional domain.

Some other findings seem relevant to mention here. The unemployment percentage because of long-term sequelae is 8%; 11% failed to continue their education as a result of the aftermath of brain damage, and another 18% stopped school for various reasons. A very small percentage needs sheltered

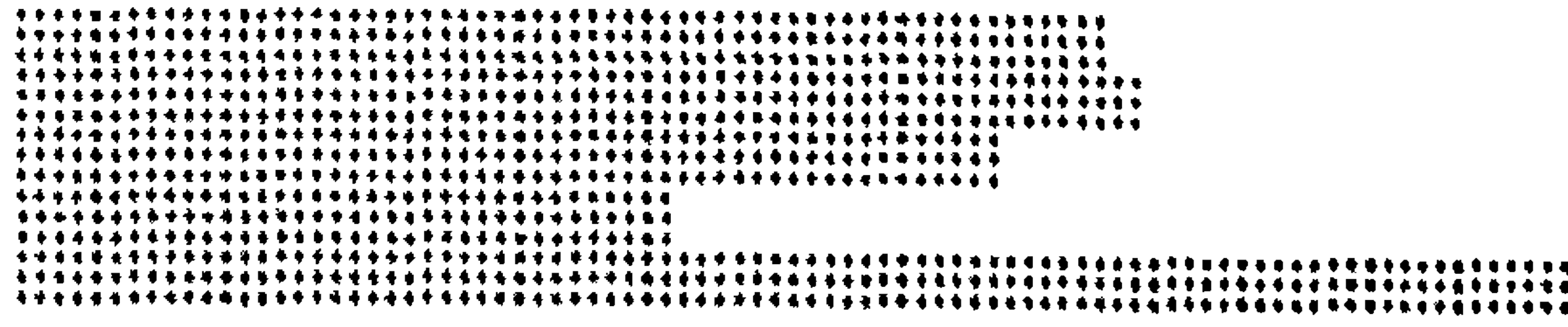
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Netherlands:



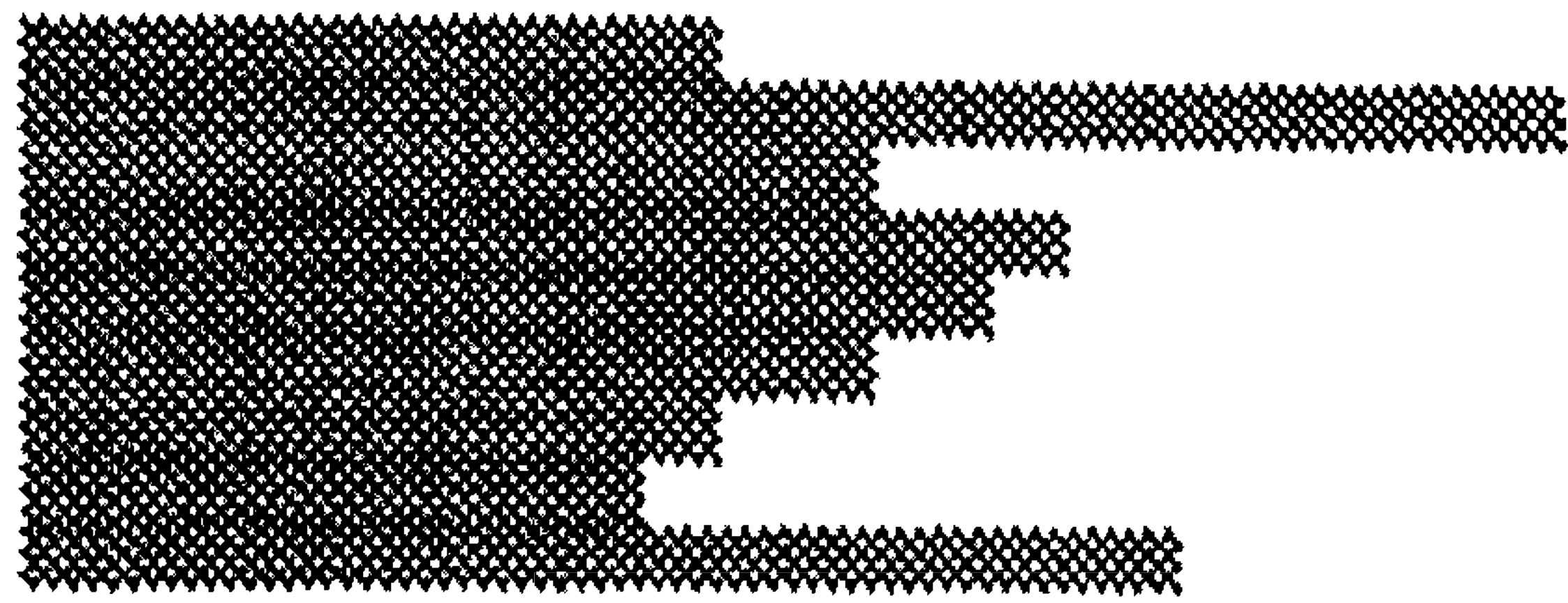
113 (Van Balen)¹⁶
79 (this study)

Great Britain:



300 (Jennett and Macmillan)²⁹
313 (id., Scotland)²⁹
270 (id., England & Wales)²⁹
179 (Lishman)⁹
430 (Field)⁶

United States:



177 (Horton and Miller)⁷
398 (Caveness)⁵
221 (Jacobs)⁸
265 (Reller and Shrank)³²
245 (Jennett and Macmillan, San Diego)²⁹
216 (id., Virginia)²⁹
180 (Kraus et al.)³¹
160 (id, inpatients only)³¹
300 (Klauber et al.)³⁰

100 200 300 400

Incidence/100,000

Figure 1. Variability of incidence of traumatic brain injury presented in the literature.

living: 18% still live with their parents, but none of them because of long term sequelae, and 80% live independently. Over 70% have a partner relation (20% are married); 51% live together with spouse and children.

Discussion

The above findings illustrate the importance of a combined disease- and disability-oriented epidemiology for TBI.

The *disease*-oriented data contribute to the community diagnosis in terms of incidence, gender, age, and age categories at risk. They indicate some international differences and national trends. As will be discussed below, these may be the effect of different research strategies and of primary preventive measures.

The epidemiology of *disability* provides data concerning long-term sequelae. Over 67% of the MA-TBI patients experience at least one disability. For 90% of these TBI victims there were no rehabilitation services.¹⁶ As rehabilitation is aimed at prevention or reduction of disability, these data should have implications for planning rehabilitation services. It will be clear that the development of these services should not be based solely on disease-related information such as 'disposition at time of discharge'. Indeed, the use of that kind of information would lead to inadequate planning, since it would imply a rehabilitation-need for only 2% of TBI patients. It is here that a

disability-oriented epidemiology of TBI shows its surplus value. This topic will be further elaborated in the last part of this text.

DISEASE

Compared to the disease-related data of selected US studies,¹² the sex differences are less pronounced in The Netherlands. However, age differences and persons at risk show the same pattern in both countries. Although Sorensen and Kraus¹² in their review noted that, even within the US, considerable variation in incidence rates, ranging from 132 per 100 000 in the state of Maryland to 367 per 100 000 for the Chicago-Evanston area, these rates are still well above the Dutch data. As illustrated in Figure 1 the Dutch incidence figures are also considerably lower than those in the US or Great Britain. This may be due to differences in definition of TBI, search strategies, and registration policies (see also refs. 13 and 18), but also because of preventive measures. Motorcycle-helmet legislation, for example, has been in existence in The Netherlands since 1975.

More recent preventive actions and improvements may have contributed to the decrease of incidence rates in The Netherlands from 112.6 in 1984 to 78.8 in 1991 (minus 29%). Among these are the ongoing development of performance standards for helmets (materials and techniques of manufacture), together with increased knowledge of mechanisms of brain injury and a better understanding of impact-energy

Table 5. Traffic accidents and alcohol-related traffic accidents with personal injuries or death for at least one person in The Netherlands in 1985 and 1991.

	Causing personal injuries			Causing death		
	Total (A)	Alcohol-related	Percentage of (A)	Total (B)	Alcohol-related	Percentage of (B)
1985	42 348	3 684	8.7	1 323	185	14.0
1991	40 649	2 753	6.8	1 155	98	8.5
Change	- 4%	- 25%		- 13%	- 42%	

Source: Centraal bureau voor de statistiek, 1994³⁵

handling.³³ Further, protective headgear has become common equipment for some sports.

Alcohol-related injuries have been a major topic in the past few years, in The Netherlands as well as in other countries. According to Jernigan,³⁴ US studies have found positive blood-alcohol levels in 35–67% of the patients presented to emergency departments or admitted to hospitals because of head injuries. In The Netherlands, strict legislation on maximum alcohol promilages in blood samples of road users has been in effect for the past decade. Furthermore, there have been numerous advertising campaigns emphasizing the negative consequences of alcohol consumption, mainly by means of television spots and billboards along the road. It is interesting that, because of these measures, there is an increasing demand for non-alcoholic beverages which has triggered commercial interest in these products. In particular non-alcoholic beers have become increasingly popular.

Although nationwide data concerning the cause of the brain injury are not available, traffic accidents are responsible for 72% of the MA-TBIs in this study, and for 67–71% in an earlier study.¹⁴ The data indeed support the presumed effect of the described preventive actions, considering the 15% increase in the total traffic kilometres of the Dutch population from 1985 to 1991, the decrease of traffic accidents with personal injuries, and the very significant reduction of alcohol-related accidents causing injuries or death³⁵ (see Table 5). The previously mentioned primary preventive actions may also play a role in the decline of the mortality rate, which dropped from 2.6/100 000 in 1982 to 1.5/100 000 in 1991 (minus 42%). In the US the mortality rate for the years 1979–1986 was 5.5/100 000.³⁶ The lower Dutch mortality rate might be the result of different incidence rates. However, the country has more than 140 well-equipped general hospitals within its 35 000 km² and also has a dense network of ambulance services. Since these services can be on the scene of the accident within 30 minutes, they probably play a significant role in secondary prevention.

In conclusion, decreasing morbidity and mortality rates seem to reflect the positive effects of primary preventive measures. While demographic data may provide a reference

for further preventive actions, and for the adjustment of planning emergency and acute-care units, they are unable to provide a reliable basis for the planning and evaluation of long-term facilities, as will be shown in the following section.

DISABILITY

In addition to emergency and acute-care facilities a comprehensive service for the rehabilitation of brain-injury survivors should include early inpatient rehabilitation, inpatient behavioural rehabilitation, other residential facilities, and outpatient services providing for physical programmes, cognitive remediation, behavioural modification, vocational rehabilitation, and comprehensive outpatient rehabilitation.³⁷ Long-term care resources that are needed include supported accommodation, stimulating day centres, sheltered workshops, and relief care facilities.³⁸ It is not the purpose of this article to design such a comprehensive service (but see e.g. ref. 39). However, it should be clear that such a blueprint cannot be based solely on disease-related epidemiological data. The surplus value of a disability-oriented epidemiology with respect to the planning of health-care facilities will be demonstrated by some examples.

There is a lack of comprehensive facilities for cognitive and behavioural rehabilitation. This is remarkable since long-term situational, cognitive and behavioural disabilities are present in at least 67% of the MA-TBI population in this study, whereas 92% were discharged to their homes after hospital admission. Furthermore, only 10% received any rehabilitation at all after the acute-care period, which points towards the necessity of reorganizing rehabilitation services. The data permit some comments pertaining to the direction of such a reorganization.

As only a very small percentage of the participants needed sheltered living, and 80% live independently of their parents, the adjustment, in quantitative terms, should be primarily realized by *outpatient* services that provide functional assessment and rehabilitation. As the mean hospital admission time is only 2 weeks (see also Table 3), assessment

is predominantly connected with disease-related variables. During these first weeks post-onset the clinical manifestations of a post-traumatic syndrome may fade away. However, an integrated neurological-neuropsychological approach in the acute-care period, which is aimed at disease-related variables as well as impairments, may reveal subclinical manifestations of a reduced information-processing capacity which are not disabling in the hospital setting, but which may force the individual to develop compensatory strategies once he or she picks up daily life. Indeed, the combination of an apparently stable and healthy physical condition with subtle impairments, e.g. the undue tiredness associated with brain injury, can lead to repeated minor failures and secondary psychological effects including loss of confidence, depressed mood, and over-compensation. As these failures are often not attributed to the sequelae of brain injury by the patient, relatives, or employers, the creation of a standardized safety net within the first 3 months after hospital discharge is proposed. This would consist of a comprehensive disability-oriented follow-up assessment. If, after taking into account the earlier assessment results, a disability is apparent, or the patient is deemed to be at risk, one should be able to refer the patient and the relatives at this time to rehabilitation facilities.

The magnitude of situational, behavioural, and cognitive disabilities seems to emphasize the importance of *cognitive remediation*. This is, as conceptualized by Ben-Yishay and Diller,⁴⁰ not only a theoretical concept, but also a body of remedial intervention techniques aimed at treating impairments and disabilities. Several years after the injury, long-term sequelae should be regarded as the result of a complex interaction of primary organic symptoms and secondary consequences such as reactions to the awareness of the disabilities, responses to the experience of loss, and environmental reactions.⁴¹ This seems particularly applicable for behavioural, emotional, and cognitive disabilities. As time passes, the likelihood of non-organic psychological factors being involved increases.⁴² Indeed, appropriate intervention at an early stage may reduce or even prevent these. It is hypothesized that an early comprehensive, cognitive-remediation programme would have a major impact by providing an accurate appraisal of a patient's disabilities, which would have a positive influence on how the patient and the environment reacted to them. This is an important starting-point for the relearning of skills, the learning of compensating strategies, personality rebuilding, and environmental adjustment.

As there are no reasons to suppose that a substantial decrease will occur in the number of traumatic brain injury survivors who need sheltered living ($\pm 2\%$), society has to seek an answer for this growing population which per year is equivalent to $n = 25-50$, one complete ward at the least (in

a country with 15 million inhabitants). In addition, it should be realized that although most brain-injured patients needing supervision are content to live with their families,³⁹ sometimes the disabilities exceed the capacity to provide sufficient care, particularly as the relatives become older. The proportion of such a delayed need for institutionalized sheltered living is unknown, but should not be underestimated.

Statistics such as a forced unemployment rate of 8% and the impossibility for at least another 11% of the respondents to continue education because of long-term sequelae cannot be derived from a disease-oriented epidemiology. However, in terms of total life-time costs⁴ these figures are most important. The potential loss in earnings, expense to society, and loss of quality of life is enormous. Unemployment is an expensive and disrupting factor, especially when other variables constituting self-esteem, e.g. the ability to love and play, are also threatened. Max *et al.*⁴ used the human capital approach to calculate indirect costs to arrive at an average total life-time cost of \$84 871. In this approach the individual is seen as producing a stream of output over time that is valued against market earnings or the imputed value of housekeeping services. Indirect costs, therefore, concern a potential loss of earnings due to long-term disabilities. Direct costs are related to transportation by ambulance, primary and secondary hospital admissions, treatment medication, home care, and social security benefits. In this study an average of \$51 062 has been calculated. However, the total life-time costs for a severe brain-injured person may easily be tenfold the average costs.

Fortunately, the concept that individuals with moderate or even severe TBI can be returned to successful employment is growing; vocational rehabilitation programmes for persons with TBI have already shown their usefulness in terms of return to work with selected patient groups (e.g. refs, 24 and 43). Although the available research does not permit work re-entry prognosis to be made for all moderate TBI patients,⁴⁴ there is sufficient information available concerning meaningful job placement, intervention, and training at the workplace.⁴⁵ Furthermore, according to Abrams *et al.*,⁴⁶ the economics of return to work following vocational rehabilitation after TBI are worth the investment, in terms of outcome and the ratio of the total taxpayer benefit to the costs of operating the programme and costs to the state.

In conclusion, the data give sufficient support to regard the effects of TBI as being chronic for many patients. As shown by the examples given, a disability-oriented epidemiology provides more relevant data than an epidemiology of disease when possible approaches are investigated that will prevent or reduce the long-term sequelae of TBI. For this reason such data should be given the attention which TBI patients deserve.

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