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Disability in young adults following major trauma: 5 year follow up of survivors

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Abstract

Background: Injuries are a major cause of mortality and morbidity in young people. Despite this, the long-term consequences for young survivors of severe injury are relatively unexplored.

Methods: Population based cohort study involving 5 year post injury structured interview of all cases of major trauma (Injury Severity Score > 15) identified retrospectively for 12 month period (1988 to 1989) within former Yorkshire Health Authority area of the United Kingdom.

Results: 125 individuals aged 11–24 years at time of injury were identified. Of these, 109 (87%) were interviewed. Only 20% (95% CI 14–29%) of those interviewed reported no disability. Mean Office of Population Census and Surveys (OPCS) disability score of the remainder was 7.5 (median 5.8, range 0.5 to 19.4). The most commonly encountered areas of disability were behaviour (54%, 95% CI 45–63%), intellectual functioning (39%, 95% CI 31–49%) and locomotion (29%, 95% CI 22–39%). Many respondents reported that their daily lives were adversely affected by their health problems for example, causing problems with work, 54% (95% CI 45–63%), or looking after the home, 28% (95% CI 21–38%). Higher OPCS scores were usually but not always associated with greater impact on daily activities. The burden of caring responsibilities fell largely on informal carers. 51% (95% CI 42–61%) of those interviewed would have liked additional help to cope with their injury and disability.

Conclusion: The study has revealed significant disability amongst a cohort of young people 5 years post severe injury. Whilst many of these young people were coping well with the consequences of their injuries, others reported continuing problems with the activities of daily life. The factors underpinning the young people's differing experiences and social outcome should be explored.

Background

Injuries are a major cause of morbidity and mortality in young people [1]. Injuries are the leading cause of death in those aged less than 35 years, causing around 5,000 deaths in this age group in England and Wales each year

[2]. Many more people suffer serious non-fatal injury resulting in some 720,000 hospital admissions per year [3] and in excess of 6 million attendances at A&E [4]. The cost to the NHS of treating traumatic injury is considerable – around £1.2 billion per year, some 7% of its annual

budget [5]. The true economic cost to the nation will be higher as many of those injured will suffer permanent disability limiting their ability to fulfil their full economic potential.

Young adult survivors of severe trauma are of special interest. Reduced economic earning power due to trauma related disability in a young adult poses a significant loss to the nation and places considerable long-term burdens on the young person and their immediate family and friends. Furthermore, young disabled survivors of trauma may have particular social, emotional and clinical needs that may not be adequately met by routine service provision. Despite the relatively high injury burden that falls on young people, the long-term consequences of traumatic injury for young survivors are relatively unexplored.

The prevalence of disability and handicap among survivors of serious injury occurring within the former Yorkshire Health Region of the United Kingdom (UK) has been described [6]. Five year follow up revealed a considerable burden of continuing disability among these survivors with 81% experiencing some form of measurable disability. Of this cohort, a high proportion of the continuing disability was seen in adolescents and young adults. This paper will focus solely on the outcome at follow-up of this group of young people (aged 11–24 years at time of injury), providing the first detailed description of the disability experienced by a cohort of young adult survivors of major trauma within one geographical region of the UK.

Methods

The detailed method of this study has already been described elsewhere [6]. Briefly, in 1990 a cohort of cases of major trauma, defined as an injury severity score (ISS) [7] of greater than 15 was identified retrospectively from with the former Yorkshire Regional Health Authority area for the 12 month period September 1988 to October 1989 [8]. In the original study of major trauma, a three-stage process was used to identify cases: a) multiple data sources were used to trauma cases attending the 16 A&E departments within the Yorkshire Regional Health Authority Area including A&E registers, casualty cards, admissions registers, tertiary referral centres, ambulance, police and coroner records; b) all case identified in step one were filtered using the MTOS(UK) criteria [9] (ICU admissions, secondary transfer, death, inpatient stay > 3 days); c) all cases meeting the MTOS inclusion criteria were reviewed and assigned an ISS. Those with a score of greater than 15 were included in the trauma study.

968 cases of major trauma were identified by this review. Of these 337 were pre-hospital deaths. Of the 631 individuals who reached hospital alive, 260 subsequently died of

their injuries, leaving 367 cases who were recorded as surviving to be discharged from acute hospital care. The case notes of all 367 survivors were re-accessed at 5 years. A standardised proforma was used to collect further information on the index admission, subsequent care and current address. The subject's general practitioners were also contacted to seek their agreement to contact their patients and to confirm that the subject was still alive. Local Research Ethics Committee approval for the study was obtained from the subject's district of residence.

Face-to-face interviews were based upon the Office of Population, Census and Surveys' (OPCS) national survey of disability in Great Britain [10]. The OPCS disability scale was developed to provide a measure of overall disability severity across a range of different types of disabilities. The scale is used to assess disability in thirteen areas: locomotion, reaching and stretching, dexterity, seeing, hearing, personal care, continence, communication, behaviour, intellectual functioning, consciousness, digestion, and disfigurement. For each area, a severity score is recorded based on a series of judgements by people with disabilities and those caring for them. For each individual, the three highest scores are then combined to provide a weighted overall severity score. Using this overall severity score, a disability severity category can be derived. The severity categories range from 1 (least severe) to 10 (most severe). Examples of typical types of disability for the different severity categories are given in the appendix. SPSS Version 9 and Confidence Interval Analysis software were used in data analysis [11,12]

Results

The full cohort profile has been described elsewhere [6]. Four of the original 367 cases were excluded at follow up due to duplication due to changes in name in the case notes. Of 363 subjects eligible for follow-up, 125 (34 %) were aged 11 – 24 years at the time of injury. Of these, 109 (87%) were successfully traced and interviewed. This compares with an 84% follow up rate for the total cohort. Of those age 11 to 24 years who were not followed up (n = 16): one was found to have had an injury which did not meet the severity criteria and should therefore not have been included in the original cohort; two had died; one had a psychiatric condition which made follow up inappropriate; 4 were living abroad or at distant addresses; 7 refused and for one no medical record could be traced.

Demographic profile

The mean age of those interviewed was 24.6 years (range 16 – 31 years). 82% of those interviewed were male (90 male, 19 female) and all but one respondent described their ethnic group as 'white'. The remaining respondent described his ethnic group as 'mixed origin'. 25 (23%) had been aged 16 years or below at the time of injury.

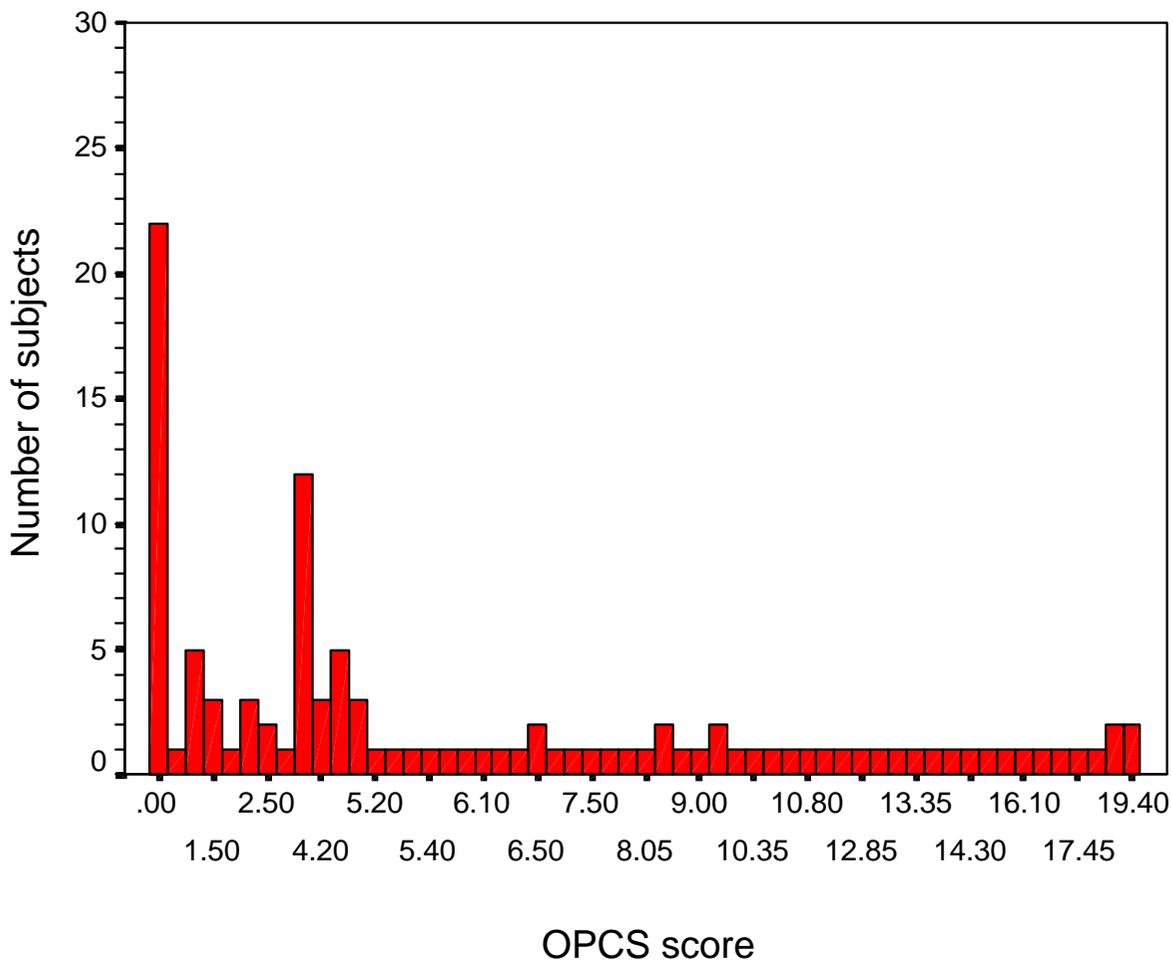


Figure 1
OPCS scores for subjects at follow up (total group n = 109)

Injury characteristics

For all causes of trauma, males were more frequently represented than females. Motorcycle accidents were the most common cause of trauma resulting in 30% of all injuries in the survivor groups. Other causes of trauma included other vehicles road traffic accidents (27%), pedestrian trauma (12%), bicycle (8%), sport (8%), occupational (7%), assault (3%), and other (5%). 24 (22%) of those interviewed reported that alcohol had played a role in the trauma that caused their injury.

ISS scores ranged from the minimum possible 16 to 51 with a median of 22. 73 (67%, 95% CI 58–75%) of those interviewed had suffered head injury, 57 (52%, 95% CI

43–64%) limb injury, 38 (35%, 95% CI 27–44%), chest injury, 34 (31%, 95% CI 23–40%) abdominal injury, 24 (22%, 95% CI 15–31%) external/skin injury and 23 (21%, 95% CI 14–30%) facial injury. The subjects stayed an average of 4 days in Intensive Care (range 0 – 27 days, median 1 days), while average length of ward stay was 22 days (range 0 – 301, median 9 days). Thus, a small number of long stay patients skew the mean length of hospital stay.

Disability at follow-up

The disability experienced by this cohort of young people as measured by the OPCS disability scale is shown in Table 1. 22 (20%, 95% CI 14–29%) of those interviewed re-

Table 1: OPCS disability scores

OPCS Domain (n = 109)	Mean	Std deviation	Median	Interquartile range (25–75%)
Continence	1.14	3.3	0	0 – 0
Consciousness	0.69	2.4	0	0 – 0
Personal Care	0.51	2.09	0	0 – 0
Locomotion	1.99	3.82	0	0 – 2.5
Dexterity	0.93	2.29	0	0 – 0
Behaviour	2.47	2.46	4.0	0 – 4.0
Communication	0.22	0.97	0	0 – 0
Intellectual functioning	0.92	1.46	0	0 – 2.0
Hearing	0.06	0.53	0	0 – 0
Reaching and stretching	0.21	0.67	0	0 – 0
Seeing	0.10	0.37	0	0 – 0
Eating and digestion	0.01	0.53	0	0 – 0
Disfigurement	0.04	0.14	0	0 – 0
Total	5.96	5.52	4.4	1.0 – 9.15

Table 2: OPCS disability scores for those subjects who had some form of disability

OPCS Domain (n = 87)	Mean	Std deviation	Median	Interquartile range
Continence (n = 14)	8.89	4.02	11.5	4.0 – 11.5
Consciousness (n = 10)	7.5	3.38	8.5	6.0 – 10.1
Personal Care (n = 8)	7.0	3.91	8.25	3.0 – 10.6
Locomotion (n = 32)	6.79	4.14	7.5	3.0 – 11.5
Dexterity (n = 18)	5.61	2.35	6.5	5.5 – 6.5
Behaviour (n = 59)	4.57	1.23	4.0	4.0 – 6.0
Communication (n = 7)	3.5	1.87	2.0	2.0 – 5.5
Intellectual functioning (n = 43)	2.34	1.44	2.0	1.0 – 3.5
Hearing (n = 3)	2.17	2.89	0.5	0.5 – 5.5
Reaching and stretching (n = 11)	2.09	0.7	2.5	1.0 – 2.5
Seeing (n = 8)	1.37	0.35	1.5	1.5 – 1.5
Eating and digestion (n = 2)	0.5	-	0.5	-
Disfigurement (n = 10)	0.5	-	0.5	0.5 – 0.5
Total (n = 87)	7.5	5.19	5.85	4.0 – 10.8

ported no long-term disability. Of the remainder, mean OPCS disability score was 7.5 (range 0.5 to 19.4, median 5.8, interquartile range 4.0–10.8). Thus, the data is skewed to the right (see Figure 1). Table 2 shows the distribution of OPCS scores among those subjects who reported some form of disability.

28 subjects (26% of total, 95% CI 18–35%) reported disability in one OPCS domain, 23 (21%, 95% CI 15–30%) reported disability in two OPCS domains and 36 (33%, 95% CI 25–42%) reported disability in three or more domains. When the OPCS scores were converted into OPCS categories, 44% (95% CI 35–53%) of respondents had OPCS severity categories of 3 or greater, while 16% (95% CI 10–24%) had categories of 7 or greater. The most commonly encountered areas of disability were behaviour

(54%, 95% CI 45–63%), intellectual functioning (39%, 95% CI 31–49%) and locomotion (29%, 95% CI 22–39%). Examples of the type of limitations reported are shown in Table 3.

Home circumstances

At follow up, 66 (61%, 95% CI 51–69%) of those interviewed were single, 40 (37%, 95% CI 28–46%) were married or co-habiting and 3 (3%) were separated or divorced. Of those who were not living with a partner, 13 were living alone, 51 with their parents and 5 with friends/flatmates. 19 (17%, 95% CI 12–26%) reported that their home had been adapted because of their specific health needs. Adaptations included ramps, stairlifts, hoists, handrails, modifications to the bathroom, widened doors and special bedding and seating.

Education

23 (21%, 95% CI 15–30%) respondents reported that they were still at school at the time of their injury. At 5 year follow-up, 5 of this group were still in full-time education. 7/18 (38%) of the remainder went on to leave full-time education with no qualifications compared to 18/80 (22%) of those injured after leaving school (95% CI for difference -0.05 to 0.4). Of the remaining 6 cases, 3 were injured after leaving school but were in full-time education at follow-up, while 3 respondents offered no information.

Employment

Of those who had left full-time education (n = 101), 49 (45% of total cohort) reported that they were currently in paid employment, while a further 2 were waiting to take a post. Of the remaining 50, 19 (17% of total, 95% CI 12–26%) reported that their disability made it impossible for them to work, although 9 of these people said that they would be able to undertake sheltered or part-time work if it were available. A further 25 (23% of total, 95% CI 16–32%) said that they had not been able to find suitable paid employment. Of the remainder, 3 people were looking after the home or family, 2 were in part-time education, and 1 person offered no information as to his/her employment status.

Impact on daily life

A considerable number of the survivors interviewed reported that their daily lives were adversely affected by health problems (Table 4). Unsurprisingly, those reporting that they experienced problems had higher mean OPCS scores than those who reported no problems. However, this was not universal – some people with high OPCS scores reported no problems while some people with low scores experienced problems.

A small number of those interviewed reported more severe problems including finding simple activities of daily life difficult or impossible. For example, 19 (17%, 95% CI 12–26%) respondents found having a bath difficult or impossible, 20 (18%, 95% CI 12–27%) found shopping for food difficult or impossible, 13 (12%, 95% CI 7–19%) were unable to prepare a meal unaided and 7 (6%, 95% CI 3–13%) needed help getting to the toilet. The burden of supporting the young people with these daily activities fell largely on close relatives with parents providing the most assistance 53% (95% CI 48–59) (of total helpers), siblings 16% (95% CI 12–20), paid help 11% (95% CI 8–15), voluntary helpers 8.3%, (95% CI 6–12), spouses/partners 7.6% (95% CI 5–11), son/daughter 2% (95% CI 1.2–5) and others 2%. Informal carers were also reported to have been the most important people in helping the subject cope with their trauma and disability. 71 (65%, 95% CI 56–73)) respondents reported that family and

friends were the most important people helping them to cope with the trauma, compared to 21 (19%, 95% CI 13–28) who felt that a professional carer (s) had been of most help.

Continuing care / Support

26 (24%, 95% CI 17–33) of those interviewed reported that they were still attending hospital for follow-up care 5 years after the initial trauma. However, only a relatively small number reported on-going use of other services with only 10 people reporting that they had received help from community health services in the previous 12 months. 56 (51%, 95% CI 42–61) respondents reported that there was additional help that they would have liked to have received in the past or currently (Table 5).

Discussion

Injuries are a major cause of death and disability among young people. The WHO estimates that some 5.8 million people died of injuries in 1998 [13]. This figure is predicted to rise over the next 2 decades to 8.4 million, largely because of predicted rise in men in the 15–29 year age group [14]. Injuries are also an important cause of long-term disability worldwide, with much of the burden once again falling on the young [13]. Despite the higher risk of injury faced by young people, relatively little is known about the long term impact of trauma on this age group.

In 1993, Barker and Power used data from the National Child Development Study to ascertain a UK population prevalence of permanent disability following accident in those aged 16–23 years of 28 per 1000 [15]. Injury occurring in young adulthood was found to be an important cause of long-term disability as between a third and a half of subjects with onset of disability after the age of 16 had injury as a cause. However, only limited information was collected as to the nature of the disability experienced. In the only other published UK population based study of the long-term outcome of major trauma, Braithwaite reported that 1 in 2 people had moderate, severe or very severe disability [16]. They did not however, describe the degree or nature of the disability experienced by young people within the cohort. Other papers have focused only on specific types of trauma (usually head or brain injury) [17–20] or on younger age groups [21–24].

Only 20% of the young people in this cohort experienced no disability. Almost half of the remainder had OPCS severity categories of 3 or greater, while almost 1 in 7 had severity scores of 7. OPCS 'pen pictures' to indicate the levels of disability experienced at these levels are given in the appendix.

Many of those interviewed either had no disability, or experienced little or no impact on their daily life as a result

Table 3: Examples of limitations reported

Locomotion	<ul style="list-style-type: none"> 40 (37%, 95% CI 28–46) people reported that they had some form of locomotion problem that was the result or had got worse since accident including; 10 who were unable to walk at all and 5 who could only walk a few steps. 20 (18%, 95% CI 12–27) reported that they used some sort of aid to walk or get around including 13 (12%, 95% CI 7–19) who used wheelchairs 14 (12%, 95% CI 8–20) of those able to stand reported that they experienced difficulty with balance and falls
Dexterity / Reaching	<ul style="list-style-type: none"> 23 (21%, 95% CI 15–31) people reported that they had difficulty holding / gripping things as a result of the accident including; 13 (12%, 95% CI 7–19) who found it difficult or impossible to serve food from a pan, 11 (10%, 95% CI 6–17) who reported difficulty teeing a bow in laces / piece of string and 7 who had difficulty holding a pen or pencil 18 (16%, 95% CI 11–25) people reported difficulty using arms to stretch or reach for things
Sight	<ul style="list-style-type: none"> 6 (5%, 95% CI 3–12) reported that they experienced visual problems as a result of the accident including; 2 people who were registered blind and 1 who was partially sighted
Hearing	<ul style="list-style-type: none"> 3 people had some sort of hearing loss as a result of accident 20 (18%, 95% CI 12–27) people had difficulty with hearing ringing or buzzing noises a result of accident
Contenance	<ul style="list-style-type: none"> 15 (14%, 95% CI 9–22) people had difficulty or loss of control of bladder 10 (9%, 95% CI) people reported difficulty or loss of bowel as a result of their injuries
Behaviour	<ul style="list-style-type: none"> 25 (23%, 95% CI 16–32) people reported that ability to relate with family and others had been made difficult as a result of accident including; 12 (11%, 95% CI 6–18) people who found relationships with family difficult, 19 (17%, 95% CI 12–26) who found relationships with people outside family difficult, and 23 (21%, 95% CI 16–30) who said that they often felt aggressive or hostile towards other people
Intellectual functioning	<ul style="list-style-type: none"> 36 (33%, 95% CI 25–42) people reported some sort of difficulty with 'intellectual functioning' including 20 (18%, 95% CI 12–27) who got confused about what day or time it is, 15 (14%, 95% CI 9–22) who would be unable to tell someone else about a TV programme they had just seen, and 30 (27%, 95% CI 20–37) who said they would be unable to remember a message and pass it on correctly
Convulsion / fit	<ul style="list-style-type: none"> 11 (10%, 95% CI 6–17)) people had fitted since the injury but only 7 (6%, 95% CI 3–13) of these had had a fit in the previous 12 months

of their disability. A number, however, reported considerable limitations. Young people may have higher expectations of what they can achieve than some other age groups, for example, wanting to be able to participate in sporting activities or to lead an active social life. These expectations may result in a greater sense of restriction and handicap than other age groups. Conversely, although it might not reduce the sense of restriction felt by the individual concerned, young people may also be more likely to have a strong informal carer support network. For example, almost half of those interviewed were still living with their parents. This may go some way to explain how some of those with more severe physical disabilities reported fewer restrictions in their daily life. Response shift, where an individual's own expectations of quality of life are readjusted to meet changing life circumstances, may also be a factor in explaining the apparent paradox where some respondents with high OPCS scores reported few problems in their everyday life while others with lower scores experienced on-going difficulties [25].

The most commonly reported area of difficulty was problems with work. Almost half of those young people who were no longer in fulltime education were without a job. A third of those unemployed said that their disability made it impossible for them to work, although almost half of these respondents also felt that greater availability of sheltered / part-time work would assist their return to employment. The high proportion of men in this group of young people might have aggravated the unemployment levels as many part-time jobs are traditionally seen as 'women's roles'.

The young people also described difficulties in a variety of other areas including looking after the home, and pursuing an active social and sex life. Although not of statistical significance, those injured while still at school were also more likely to have left fulltime education with no qualifications.

Perhaps inevitably, much of the caring responsibility had been placed on informal carers – usually parents, spouses and other close relatives. For those who were more

Table 4: Reported impact on daily life

Health causing problems with....	Yes		No	
	No. (% , 95% CI)	Mean OPCS (median & range)	No. (%)	Mean OPCS (median & range)
Job/work	59 (54, 45 – 63)	8.7 (7.9, 0 – 19.4)	50 (46, 37 – 55)	2.8 (2.0, 0 – 16.1)
Looking after home	31 (28, 21 – 38)	10.8 (11.2, 0 – 19.4)	78 (72, 63 – 79)	4.0 (4.0, 0 – 16.1)
Social life	24 (22, 15 – 31)	11.0 (12.1, 1.7–19.4)	85 (78, 69 – 85)	4.5 (4.0, 0 – 18.9)
Home life	19 (17, 12 – 26)	9.9 (7.9, 3.4 – 19.4)	90 (82, 74 – 89)	5.13 (4.0, 0 – 19.4)
Sex life	23 (21, 15 – 30)	11.5 (13.0, 2.5 – 19.4)	86 (79, 70 – 86)	4.5 (4.0, 0 – 17.3)
Interests and hobbies	47 (43, 34 – 53)	8.7 (6.5, 0 – 19.4)	62 (57, 48 – 66)	3.9 (4.0, 0 – 16.1)
Holidays	26 (24, 17 – 33)	11.3 (12.9, 3.4 – 19.4)	83 (76, 67 – 83)	4.3 (4.0, 0 – 18.9)

Table 5: Type of additional help respondents reported they would have liked to have received

Nature of help	No. (% of total requests for help)
Better quality / greater quantity of health care services	31 (41)
Counselling / more emotional support for self or parents	20 (27)
More information / advice	12 (16)
More general care and support	9 (12)
Financial / physical help (eg better housing / special equipment)	5 (7)
Total responses regarding additional help required	75* (100)

*some respondents reported more than type of additional help

profoundly disabled, coping with the activities of daily life such as washing, feeding and dressing largely fell on informal carers. Very few of those interviewed reported regular assistance from formal carers. Half of those interviewed reported that they would have liked additional help to cope with their injury and disability.

The limitations of the study have been discussed elsewhere [6]. The main drawback is the reliance on recall and self-report by respondents as to the nature of their disabilities. This may introduce an element of bias. However, it has been reported that interview data correlates closely with hospital clinical assessment and are consistent over time [26]. It would also have been useful to canvass carers' views on the impact of the young person's trauma and continuing disability. However, this was beyond the scope of the study.

The study has highlighted the significant level of on-going disability experienced by young people as a result of major trauma. The cost in human and financial terms to the young people, their family and friends and to society at large is considerable. This cost must be expanded to include those bereaved of people who suffer major trauma but do not survive and those who experience less severe

injuries that can also go on to produce on-going disability. The OPCS scale has been shown to correlate with the SF36 quality of life measure, making this descriptive study potentially of value in future economic evaluations [J Connelly, personal communication, 2002]

It is unclear how many of these traumatic injuries could have been prevented or ameliorated. Trauma care has moved on since the late 1980s when these young people were injured. Advances have also been made in methods of preventing injuries. However, despite these advances, the rate of injury deaths in young people has shown relatively little improvement [27]. There is evidence to suggest that effective injury prevention measures are not always implemented [28]. Although we will never live in a risk-free world, it is likely that many young people are being injured from potentially preventable injuries.

Conclusions

This study describes the disability outcome of a population cohort of young people who have survived major trauma. The study has revealed significant on-going disability amongst this group of young people with a major impact on their lives and the lives of their immediate family. Whilst some respondents reported that they were cop-

ing well with the consequences of their injuries, others were experiencing on-going problems 5 years on from their accident. These included problems in their every day life such as finding work and leading an active social life, as well as more fundamental problems such as coping with continuing pain. Much of the burden of supporting these young people was being borne by close family and friends. The factors underpinning the young people's differing experiences and social outcome should be explored.

Competing interests

None declared.

Appendix

Examples of 'pen pictures' of typical cases in OPCS severity categories [7]

OPCS severity category 3

Man aged 47 with spinal arthritis, has difficulty putting either hand behind back to put jacket on or tuck shirt in. Cannot walk 200 yards without stopping or severe discomfort. Can only walk up and down a flight of 12 stairs if holds on. Has difficulty getting in and out of bed. Has difficulty following a conversation against background noise.

OPCS severity score 5

Woman aged 16, mild cerebral palsy, one leg 3/4 inch shorter than the other. Often gets confused about what time of day it is, can not read a short article in a newspaper, cannot count well enough to handle money, cannot watch half hour TV programme all the way through and tell someone what it was about, thoughts tend to be muddled or slow, finds it very difficult to understand strangers, can only walk up and down a flight of stairs if goes sideways to one step at a time.

OPCS severity category 7

Man aged 31 addicted to tablets. Gets so upset that hits other people, breaks or rips things up. Feels the need to have someone present all the time. Find relationships with people outside the family very difficult. Sometimes sits for hours doing nothing. Is impossible for strangers to understand. Is quite difficult for people who know him well to understand.

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References

1. **Mortality Statistics by Cause; England & Wales 1995.** London: HSMO 1996,
2. **Mortality data** Office of National Statistics 1998,

3. **Hospital Episode Statistics** Department of Health: London 1998,
4. Ward H and Christie N **Strategic review of research priorities for accidental injury** London: Department of Health 2000,
5. Department of Health NHS Executive **Burdens of Disease: a discussion document.** London: Department of Health 1996,
6. Airey MC, Chell SM, Rigby AS, Tennant A and Connelly JB **The epidemiology of disability and occupation handicap resulting from major traumatic injury.** *Disability and Rehabilitation* 2001, **23(12)**:509-15
7. Association for the Advancement of Automotive Medicine **The Abbreviated Injury Scale. 1990 revision** Des Plaines, IL: AAAM 1990,
8. Airey CM and Franks AJ **Major trauma workload within an English Health Region.** *Injury* 1995, **26(1)**:25-31
9. Yates DW, Woolford M and Hollis S **Preliminary analysis of the care of injured patients in 33 British hospitals: first report of the United Kingdom major trauma outcome study.** *BMJ* 1992, **305**:737
10. Martin J and White A **The prevalence of disability among adults. OPCS surveys of disability in Great Britain Report I.** OPCS Social Survey Division. London:HMSO 1988,
11. **SPSS for Windows 9.0** SPSS Inc 1989-1999
12. Bryant T **Confidence Interval Analysis** University of Southampton 2000,
13. Krug Injury E **A leading cause of the global burden of disease** World Health Organisation: Geneva 1999,
14. Murray CL and Lopez AD **Alternative projections of mortality and disability by cause 1990-2020: Global burden of disease study.** *Lancet* 1997, **349**:1498-504
15. Barker M and Power C **Disability in young adults: the role of injuries.** *J Epi Comm Health* 1993, **47**:349-54
16. Braithwaite IJ, Boot DA, Patterson M and Robinson A **Disability after severe injury: five year follow up of a large cohort.** *Injury* 1998, **29(1)**:55-9
17. Thornhill S, Teasdale GM, Murray GD and McEwen J **Disability in young people and adults one year after head injury: prospective cohort study.** *BMJ* 2000, **320(7250)**:1631-5
18. Colantonio A, Dawson DR and McLellan BA **Head injury in young adults: long-term outcome** *Arch of Phys Med Rehabil* 1998, **79(5)**:550-8
19. Massagli TL, Michaud LJ and Rivara FP **Association between injury indices and outcome after severe traumatic brain injury in children** *Arch Phys Med Rehabil* 1996, **77(2)**:125-32
20. Emmanuelson I, von Wendt L, Beckung E and Hagberg I **Late outcome after severe traumatic brain injury in children** *Pediatric Rehabilitation* 1998, **2(2)**:65-70
21. Avery JG and Gibbs B **Long term disability following accidents in childhood. A paper presented at the symposium on accidents in childhood.** *Child Accident Prevention Trust, London* 1985,
22. Gofin R, Adler B and Hass T **Incidence and impact of childhood and adolescent injuries: a population based study.** *J Trauma* 1999, **47(1)**:15-21
23. Valadka S, Poenaru D and Dueck A **Long-term disability after trauma in children** *Journal of Pediatric Surgery* 2000, **35(5)**:684-7
24. Hu X, Wesson DE, Logestty S and Spence LJ **Functional limitations and recovery in children with severe trauma: a one-year follow-up** *J Trauma* 1994, **37(2)**:209-13
25. Albrecht GL and Devlieger PJ **The disability paradox: high quality of life against all odds.** *Social Science and Medicine* 1999, **48**:977-88
26. Garrad J and Bennett AE **A validated interview schedule for use in population surveys of chronic disease and disability** *Br J Prev Soc Med* 1971, **25**:97-104
27. Nicholl J and Coleman P **Accidents.** In: *Trends in mortality and morbidity. The Health of Adult Britain* (Edited by: Charlton J, Murphy M) London: HMSO 1997, **2**:158-72
28. Roberts I **Smoke alarm use: prevalence and household predictors** *Injury Prevention* 1996, **2**:263-5

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