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**Title: CHILDREN'S BRAIN INJURY – A POSTAL FOLLOW-UP
OF 525 CHILDREN FROM ONE HEALTH REGION IN THE UK**

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Abstract

Primary objectives: to follow-up a population of children admitted to one Hospital Trust with traumatic brain injury (TBI), and compare outcomes following mild TBI with outcomes following moderate or severe TBI.

Research design: population-based postal questionnaire survey.

Methods and procedures: questionnaires were mailed to parents of all 974 surviving children on a register of paediatric TBI admissions, 525 completed questionnaires were returned (56.2%). Most children (419) had suffered mild TBI, 57 moderate, and 49 severe.

Main outcomes and results: Thirty percent of parents received no information on post-injury symptoms, and clinical follow-up was limited. Statistically significant differences were observed between mild and moderate/severe groups for cognitive, social, emotional, and mobility problems. Nevertheless, approximately 20% of the mild group suffered from poor concentration, personality change, and educational problems post-injury. Few schools (20%) made special provision for children returning after injury.

Conclusions: children can have long lasting and wide ranging sequelae following TBI. Information should be routinely given to parents and schools after brain injury.

Introduction

Traumatic brain injury (TBI) is a major public health problem and is also a leading cause of mortality or permanent disability in children and adolescents [1-3]. In the United Kingdom there are no definitive figures for the prevalence of childhood brain injury, but it has been estimated that each year approximately 300 people/100,000 will suffer a brain injury, with the figures up to four times higher amongst young children and young adults [4]. Each year, per 100,000 population, 8 people will suffer severe TBI, 18 moderate, and 150-300 mild. More recently it has been argued that these figures are likely to be an underestimate because of inadequate recording [5].

Early studies on primates indicated that due to the plasticity of the young brain acquired brain injuries caused little observable functional loss in long term outcome [6,7]. However, more recent studies have shown that brain injury in children can lead to persistent cognitive and neurobehavioural deficits and intellectual, academic and personality adjustment problems [8-11]. Fletcher and colleagues also found a high incidence of emotional and behavioural problems in children after brain injury [12]. Stress and negative effects on psychosocial functioning of the family of the child with a brain injury have also been widely reported [13-15].

There is disagreement as to whether mild brain injury can lead to long term problems or deficits [16]. Chadwick and colleagues in their longitudinal prospective study of children with TBI found no increased risk of neurocognitive sequelae following mild TBI [17]. However, other investigators have provided evidence of cognitive and behavioural deficits [18,19]. It is therefore evident that some children demonstrate lasting problems after a mild brain injury whereas others do not.

Most studies of outcomes following childhood brain injury have looked at small groups of children. The few large scale surveys which have been carried out often used data from clinical records without making contact with patients [20,21]. However, postal questionnaire techniques have proved successful in a recent population-based study of adults following brain injury [22].

The current study was designed to carry out a postal follow-up of all children admitted with a brain injury in one health region to investigate outcomes following mild, moderate, and severe brain injury one to six years post-injury. The aims were to measure the information and follow-up needs of families, to identify issues surrounding return to school following brain injury, and to compare outcomes following mild TBI with outcomes following moderate or severe TBI.

Method

The population of children forming the study group was identified utilising a comprehensive Brain Injury Register of all children admitted to North Staffordshire Hospital NHS Trust with TBI between November 1992 and December 1998. Between July 1998 and May 1999, a postal questionnaire was sent to parents of all 974 surviving children on the Register aged 5-15 years at the time of the injury. This age group was selected as pre-morbid functioning would be difficult for parents to estimate for children under 5 years old.

Questionnaires were sent to parents or guardians of all 974 survivors together with a letter explaining the study. At the end of the questionnaire, parents were invited to tick a box if they wished to discuss any issues raised by the survey with a brain injury nurse. Four weeks later, non-responders were sent a second questionnaire and a letter encouraging them to participate.

Forty envelopes were returned as undeliverable as the addressee had moved. Of the 934 valid addresses, completed questionnaires were returned by 525 families, an overall response rate of 56.2%.

Participants

Five hundred and twenty-five children with TBI, aged 5-15 years at injury. Mean age was 9.8 years (median = 10 years, SD 3.16); and 366 (69.7%) were male. Injury severity was determined using Glasgow Coma Scale (GCS) [23] scores where recorded and/or duration of loss of consciousness. Using the British Society of Rehabilitation Medicine classification of severity [4], shown in table 1, 49 (9.3%) of the group had severe brain injuries, 57 (10.9%) moderate, and 419 (79.8%) mild.

Insert Table 1 about here

Demographic data

The population of North Staffordshire is predominantly white. The last national population census for which figures are available was carried out in 1991. This showed that only 2% of the North Staffordshire population were from ethnic minority groups compared to 5.9% of England and Wales as a whole [24]. This was reflected by our respondents, 96.7% of whom were white. Responses were received from other ethnic groups: Pakistani (N = 10, 1.9%), Asian (N = 2, 0.4%), Black African (N = 1, 0.2%), Black Caribbean (N = 2, 0.4%), Indian (N = 1, 0.2%), and Chinese (N = 1, 0.2%).

At the time of the brain injury, three quarters of parents (397, 75.6%) were married or living with a partner, 69 (13.1%) were single parents, 40 (7.6%) were divorced, and 10 (1.9%) were widowed. At the time of the postal questionnaire, the figures were similar except that more parents became divorced (63, 12%).

Postcode data was analysed using Townsend Deprivation Scores [25]. Figure 1 illustrates levels of deprivation for the group, where the higher the positive score the more deprived an area, and the higher the negative score the more prosperous. Scores were calculated for 520 families, postcode data was missing for 5. The mean score was 1.2, (SD = 2.8), compared to the national average of zero. The majority of families lived in areas with positive scores (355, 68.3%). 74 families (14.2%) lived in considerably deprived areas (scores of +3.55 and above), whereas 81 families (15.6%) lived in more affluent areas (scores of -2.4 and below).

Insert Figure 1 about here

Cause of injury

The most common causes of brain injury were falls (201, 38.3%) and road traffic accidents (143, 27.2%), especially as pedestrians (89, 17%). All causes are shown in figure 2.

Insert Figure 2 about here

Time since injury

The Brain Injury Register has been maintained since November 1992. The postal questionnaires were sent out between 1998 and 1999, enabling us to take a snapshot of outcomes at different times post-injury. At the time of the follow-up, children ranged from ≤1 year post-injury (104, 20%) to 6 years post-injury (57, 11%). The mean number of years post-injury was 3.2 (median=3 years, SD 1.64). Figure 3 shows the number of children followed up at different times post-injury. For years 1-5 post-injury, the mean was 93.4 children/year.

Insert Figure 3 about here

Measures

A postal questionnaire was designed and piloted to capture eight categories of information:

1. Details of other injuries suffered at the time of the TBI
2. Information given to parents
3. Follow-up care received from primary, secondary, and community services
4. Social Services input
5. Return to school
6. Changes in the child following the brain injury using a symptom checklist
7. Employment post brain injury
8. Effects on the family, including siblings

The list of symptoms related to brain injury was devised using a combination of commonly reported problems identified by a large sample of adults with brain injury and from the literature on childhood brain injury [26,27]. The schools section was devised in conjunction with teachers, an education consultant, and an educational psychologist.

Statistical analysis

Most questions were of a 'yes' or 'no' tick-box format to ease the burden on respondents. Cross-tabulations were carried out on yes/no responses and the Chi-Square statistic calculated using SPSS Version 8.0 [28].

Results

Other injuries

Two hundred and nine children had suffered other injuries at the time of the brain injury, representing 39.8% of the sample. In the mild group, 145 children (34.6%) had suffered other injuries such as broken limbs, shoulder, chest, and/or facial injuries. Other injuries were

suffered by 28 children (49.1%) in the moderate group and by 36 (73.5%) in the severe group. Chi-Square cross-tabulations revealed a significant difference between the three groups ($p=0.0001$, $X^2=29.97$, $df=2$).

At the time of the survey these other injuries were still giving problems for 62 (14.8%) of the mild group, 16 (28.1%) moderate, and 15 (30.6%) severe. Again, the Chi-Square test indicated a significant difference between groups ($p=0.002$, $X^2=12.32$, $df=2$).

Incidence of epilepsy

Only 10 children (1.9%) suffered from epilepsy. Epilepsy was a new problem since the brain injury for only eight of these. Of the new epileptics, 5 (1.2%) were mildly injured, 1 (1.8%) was moderately injured, and 2 (4.1%) were severely injured. There was no significant difference between the three severity groups.

Accident-prone children

Ninety four parents (17.9%) described their child as accident-prone before the brain injury, 76 (18.1%) mild, 13 (22.8%) moderate, and 5 (10.2%) severe. There was no significant difference between groups. After the brain injury, 105 parents (20%) described their child as accident-prone, with a considerable increase in the number of children in the severe group: 12 (24.5%) compared to 5 previously (10.2%). The number of accident-prone children in the moderate group rose from 13 to 17 (29.8%), but the numbers in the mild group remained unchanged. The differences between groups did not reach significance ($p=0.08$).

Information and Follow-up

Information received

The parents of 390 children (74.3%) were given information about the problems and symptoms their child may experience following the brain injury. Most of the parents of mildly injured children (323, 77.1%) received this information. However, under two thirds of the parents of both moderately (36, 63.2%) and severely injured children (31, 63.3%) received information. There was a significant difference between the groups, with information received by more of the mild group ($p=0.01$, $X^2=8.53$, $df=2$). The majority of parents found the information useful (366, 69.7%); however, only half of parents in the severe group found it useful. There was a significant difference between the groups with the mild more satisfied ($p=0.003$, $X^2=11.34$, $df=2$). Approximately one quarter of parents in the moderate and severe groups had other information requirements. These included requests for information on long-term effects, symptoms to look out for, and which further services may be available to help the child's recovery.

Accident prevention advice was given to the parents of 70 children (13.3%), and most found it useful. There were no significant differences between the groups.

Follow-up treatment post-injury

One hundred and fifty eight children had a clinical follow-up after the brain injury, this represented only 30.1% of the study sample. In the mild group, 91 children (21.7%) had a follow-up appointment, yet many of these were probably due to the presence of other injuries.

Follow-up appointments were offered to half of the children (29, 50.9%) in the moderate group, and three quarters of the children (38, 77.6%) in the severe group. The Chi-Square test indicated a highly significant difference between the groups ($p=0.0001$, $X^2=78.13$, $df=2$).

Only 40 children received any form of therapy following their brain injury, representing 7.6% of the whole study group. Therapy was received by 14 children (3.3%) in the mild, 8 children (14%) in the moderate, and 18 children (36.7%) in the severe group. There were high statistically significant differences between the groups ($p=0.0001$, $X^2=73.24$, $df=2$).

Parents defined ‘therapy’ in different ways, and some parents included attending hospital for MRI or CT scans. The therapeutic intervention most frequently reported was physiotherapy (19 children, 3.6%). However, in 7 cases, this was for other injuries received in the accident and unrelated to the brain injury. Only 6 children received a comprehensive rehabilitation programme, all of whom had suffered a severe brain injury (GCS 3-8). However, this represents only 12.2% of the severely injured group. Table 2 shows the follow-up and information received.

Insert Table 2 about here

Changes in attendance to primary health care services since injury

We asked parents to estimate how often they sought medical advice from their family doctor/general practitioner (GP) for their child before the brain injury. Of the 472 parents who answered this question, 189 (40%) said that before the injury they rarely sought medical advice, 195 children (41.3%) made occasional visits of 1-3 times per year, 63 children (13.3%) made frequent visits of 4 or more times per year, and 23 (4.9%) said their child had never visited their GP. Children who made frequent visits were likely to have pre-existing medical conditions such as asthma or diabetes. The data was also analysed by injury severity, dividing the children into 2 groups of mild and moderate/severe brain injury. The frequency of GP visits before the brain injury was very similar for both groups. Table 3 shows the frequency of consultations both before and after injury.

Insert Table 3 about here

Parents were also asked how often their child visited their GP after the brain injury. In the mild group there was little difference between the frequency of visits before and after injury, with 69 children (18.6%) not visiting their GP at all since the injury. For the moderate/severe group, there were larger differences whereby 15 children (14.7%) visited their GP rarely post-injury compared with 44 (43.1%) before and 16 (15.7%) visited their GP frequently compared to 12 (11.8%) previously. Three children (2.9%) were still attending a rehabilitation unit. Sixteen (15.7%) had not visited their GP since the injury.

Social Services input

Only 19 families (3.6%) said that they had been offered Social Services support after the brain injury. Support included benefits advice, help with transport, information on support groups, and provision of a social worker. Most of the recipients were in the severely injured group (10 families, 20.4%). Support had also been offered to 6 families (1.4%) in the mild group and 3 (5.3%) in the moderate group. There was a highly significant difference between the severity groups ($p=0.0001$, $X^2=45.79$, $df=2$).

Ten families (1.9%) had a named social worker. Four of these (8.2%) were in the severe group, one (1.8%) in the moderate group, and 5 (1.2%) in the mild group. There was a significant difference between the groups ($p=0.003$, $X^2=11.41$, $df=2$).

Return to school following traumatic brain injury

All of the children in the study sample were admitted to hospital for at least 24 hours. However, not all of them missed school as the brain injury may have occurred during weekends or, frequently, during school vacations. Parents of 381 children (72.6%) reported that their child had missed school following the brain injury. In the mild group, 289 children (69%) missed school, in the moderate 47 (82.5%), and in the severe 45 (91.8%). An analysis of variance showed a significant difference between the three severity groups for the number of missed schooldays ($p=0.001$, $F=65.026$). For the mild group, the mean number of missed school days was 16.1 (median = 7, SD 5.74, range = 1 - 300 days). For this group, a high number of missed days was usually due to other orthopaedic injuries. For the moderate group, the mean number of missed school days was 30.6 (median = 14, SD 43.76, range = 2 - 182 days), and for the severe group, the mean was 140.6 (median = 62, SD 128.74, range = 7 - 400 days). Four children in the latter group had not yet returned to school.

The majority of children (475, 90.5%) returned to the same school after the injury. Those not returning to the same school were: severe = 8 (16.3%), moderate = 2 (3.5%), and mild = 40 (9.5%). For the mild group, the most usual reason for not returning to the same school was moving from junior to high school rather than because of the injury.

Parents of 422 children (80.4%) reported that teachers at the school were aware of the child's brain injury when he or she returned after the accident. Teachers did not know about the injury for 90 (21.5%) of the mild group, 7 (12.3%) of the moderate group, and 6 (12.2%) of the severe group.

The school made special arrangements for the child on his/her return in only 106 (20.2%) of cases. In practice, these were usually keeping the child indoors at playtimes and excusing the child from physical education. The proportion of schools making special arrangements was significantly different for the three severity groups ($p=0.001$, $X^2=54.62$, $df=2$). Just over half the schools made some special arrangements for severely injured children (27, 55.1%). For children with moderate injuries, 20 (35.1%) had special arrangements, and for the mild, 59 (14.1%). However, this was usually because of other injuries.

123 children (23.4%) were having difficulties at school in the first few months post-injury. There was a significant difference between the three severity groups ($p=0.001$, $X^2=33.47$, $df=2$). Half of the severe group were having difficulties (24, 49%), 23 (40.4%) of the moderate, and 76 (18.1%) of the mild.

Special educational needs (SENs) were identified for 38 children (7.2%), 23 children (5.5%) in the mild group, 1 (1.8%) in the moderate, and 14 (28.6%) in the severe group. However, SENs were provided for less than two thirds of these children (24, 63.2%).

At the time of the survey, *current* school teachers knew of the child's brain injury in only 207 cases (39.4%). There was a significant difference between the severity groups ($p=0.001$,

$\chi^2=39.31$, $df=2$). Teachers were aware of the injury for 138 children (32.9%) in the mild group, 33 (57.9%) moderate, and 36 (73.5%) severe.

At follow-up, 89 children (17%) were having difficulties with school work (64 (15.3%) mild, 11 (19.3%) moderate, and 14 (28.6%) severe). Ninety five children (18.1%) had been disciplined for problem behaviour at school since the injury (73 (17.4%) mild, 12 (21.1%) moderate, and 10 (20.4%) severe). Twenty seven children (5.1%) had been excluded from school since the injury (21 (5%) mild, 3 (5.3%) moderate, and 3 (6.1%) severe). There were no significant differences between the groups.

Outcomes following traumatic brain injury

Symptoms reported since the brain injury

The questionnaire contained a list of symptoms and problems believed to be associated with brain injury. Some of the items were not problems, but were included as possible changes in the child, these were: 'more outgoing', 'more sociable', 'has more friends', 'more active', and 'has fewer arguments with siblings'. Parents were asked: 'since the head injury have you noticed any of the following changes in your son/daughter? Even if you do not think they were caused by the injury', and asked to answer 'yes' or 'no'. Parents of 521 children completed this section. The results are presented in table 4. Children who suffered a mild brain injury were compared to children who had suffered a moderate or severe brain injury using the Chi Squared statistic. There were statistically significant differences between the groups on all but five dimensions. 'Getting into trouble at school' was reported by parents of mildly injured children as frequently as by parents of moderately or severely injured children. The other four non-significant dimensions were 'has more friends', 'is more sociable', 'is more active', and 'has fewer arguments with siblings'.

Insert Table 4 about here

The most highly significant differences between the two severity groups were noted for the following: 'personality change': moderate/severe = 56.4%, mild = 20.2%, 'poor concentration': moderate/severe = 51.8%, mild = 24.1%, 'memory problems': moderate/severe = 39.1%, mild = 12.7%, and mobility problems (comprising 'balance and co-ordination', 'walking' and 'running'): moderate/severe = approximately 20%, mild = approximately 5%.

Symptoms were analysed by time since injury using the Chi Squared test to measure 'symptom' X 'year since injury'. No differences were observed between the groups. Symptoms were also analysed by recent TBI (≤ 1 year post-injury) and less recent TBI (>1 year post-injury). There were significant differences between the groups for two changes, neither of them problems. More of the recently injured children were described by their parents as 'more outgoing' ($p = 0.02$) and 'more sociable' ($p = 0.03$).

Employment changes post-injury

Twenty six (5%) children were doing some form of paid work prior to the brain injury. Jobs were usually delivering newspapers or part-time shop work. After the injury, 18 youngsters continued their work. The mild group was largely unaffected, with 4.1% working before injury compared to 3.6% afterwards. Those in the moderate and severe groups were more

likely to cease work (moderate: 7% working before compared with 1.8% after, severe: 10.2% working before compared with 4.1% after). There were no significant differences between the three groups.

Effects on the family and support for families

Parents of 125 children (23.8%) received some form of help or support after the injury. Help was received by parents of 83 (19.8%) children with a mild injury, 19 (33.3%) moderate, and 23 (46.9%) severe. There were significant differences between the three groups ($p=0.0001$, $X^2=20.996$, $df=2$).

Help and support was most usually provided by family members (106, 84.8% of those receiving help), mainly by the child's mother's mother (81, 64.8%) and/or father (42, 33.6%). Fifty one (9.7%) parents said that they needed help but did not receive it. Of these most were in the severe group (13, 26.5%), followed by parents in the moderate group (12, 21.1%). Twenty-six parents (6.2%) in the mild group said they needed help but did not receive any. Significant differences were observed between the groups ($p=0.0001$, $X^2=30.04$, $df=2$).

Forty three parents (8.2%) had changed their working hours because of their child's brain injury. Working hours changed for parents of only 17 mildly injured children (4.1%), but for over one quarter of parents of moderately injured children (15, 26.3%), a higher proportion than parents of severely injured children (11, 22.4%). There were highly significant differences between the groups ($p = 0.0001$, $X^2 = 47.67$, $df=2$).

Eighteen parents (3.4%) changed or gave up their job because of their child's brain injury. Change or loss of job affected 8 parents (16.3%) in the severe group, 5 (8.8%) in the moderate, and 5 (1.2%) in the mild. There were highly significant differences between the groups ($p=0.0001$, $X^2=28.86$, $df=2$).

Parents were offered the opportunity to discuss the issues raised by the questionnaire with a brain injury nurse adviser. One third of parents (182, 34.7%) took up this offer. Of these, 131 (31.3%) were in the mild group, 23 (40.4%) moderate, and 28 (57.1%) severe.

Effect on siblings

Four hundred and eighteen children had at least one sibling. The mean number of siblings was 2.33 (median = 2, SD 1.08).

Initial stress or problems

Siblings in 79 families (18.9%) suffered stress or problems in the first few months after their brother or sister had a brain injury. Examples included nightmares, anxiety, fear, behavioural problems, jealousy of the attention the injured child received, and guilt amongst some older siblings who were with the injured child at the time of the accident. One sibling attempted suicide. Counting only those children with siblings, in the severe group, siblings of over half the patients, (22, 56.4%) had problems or stress, as did one third of siblings of children in the moderate group (16, 33.3%) and 41 siblings of children in the mild group (12.7%). There were highly significant differences between the groups ($p=0.0001$, $X^2=52.25$, $df=2$).

Current stress or problems

Only 24 families (5.7%) reported that siblings were currently having problems. Examples included anxiety, stress, including post traumatic stress disorder (PTSD), and behavioural problems, including getting into trouble with the law. Of the children with problems, 7 (17.9%) were siblings of severely injured children, 5 siblings (10.4%) of moderately injured children, and 12 siblings (3.7%) of mildly injured children. There were significant differences between the groups ($p=0.003$, $X^2=16.15$, $df=2$).

Discussion

The first aim of this study was to investigate information and follow-up needs of families. We found that approximately 30% of parents claimed that they were not given information on brain injury or what to look out for. Parents of mildly injured children were most likely to receive information as an information sheet is usually routinely given at discharge from hospital. One third of parents of moderately and severely injured children did not receive any information. Some of these children were transferred back to their referring hospital after discharge from North Staffordshire and may have been missed. It is of concern that many of these parents claimed to have no idea what to expect following their child's serious brain injury.

Clinical follow-up was only offered to 21.7% (91) of the mild group. However, the majority of these children were admitted for observation and were discharged the next day, which is an increasingly used management practice for mild paediatric brain injury [29]. Of greater concern is that, according to their parents, only half of the moderately injured children (50.9%) received a follow-up appointment. Furthermore, only 14% (8) of these children received any therapeutic intervention.

Most of the severely injured group had a clinical follow-up; however, 22.4% (11) did not, again possibly because they were transferred back to their referring hospital. Just over one third of these children received therapy, with only six severely injured children (12.2%) receiving specialised rehabilitation. This finding is surprising considering that it is known that following a severe brain injury children are likely to have many persistent cognitive, neurobehavioural, academic, and social problems [17,30,31]. However, in the United Kingdom, there are few specialist rehabilitation facilities for children, and most of these are privately managed.

Parents of mildly injured children, on the whole, did not seek more appointments with their general practitioner for their child after the injury. There was a small increase in GP appointments for moderately and severely injured children.

The second aim was to identify issues surrounding return to school following a brain injury. The responsibility for informing the school about a child's brain injury lay with the parent, except in the most severe cases. If the injury occurred during the school vacation, the school may not be informed. On initial return to school, most school teachers were aware that the child had suffered a brain injury (80.4%, 422). However, at the time of the survey, this figure had halved to only 39.4% (207), comprising one third of teachers of the mild group, over half of teachers in the moderate group, and almost three-quarters of teachers of the severe group. As a child moves from school year to school year, he or she gains new teachers, and it was

evident that information about the brain injury was not passed on from teacher to teacher. Given the persistent nature of cognitive and behavioural problems following a moderate or severe brain injury, which has been identified by other studies, this is an area of concern [13,14,32]. It was notable that 95 children had been disciplined for problem behaviour since returning to school after the brain injury, approximately 20% of children in each severity group, and 27 children had been permanently excluded from school.

Recent research has found inadequate educational provision for children after brain injury largely due to inaccurate information, communication, and training [33,21]. We found that even when special educational needs (SENs) were identified, they were only actually provided for in under two thirds of cases (24 children, 63.2% of those identified with SENs). Only 20% of schools made any special provision for a child returning after a brain injury. Even if the TBI was severe, special arrangements were made for only half these children (27, 55%). School teachers tended to make special arrangements for children who had visible physical injuries, such as fractures to arms or legs. However, when the injury was invisible, few children had been offered any help. School teachers should be provided with a list of possible cognitive and behavioural symptoms following TBI, to help them identify children who need extra educational assistance, or help with behavioural problems, and hopefully help to prevent inappropriate exclusions from school.

The third aim of the study was to identify the proportion of children with a mild brain injury who suffer problems associated with brain injury and to compare their outcomes with those of the moderate and severe group. Chadwick and colleagues found that age, sex and social class had no significant effect on the course of recovery [17], consequently for our analysis it was deemed sufficient to group participants by injury severity alone.

Parents were asked if their child had changed on a number of dimensions since the brain injury. For most items, there was a statistically significant difference between the groups, with more changes reported amongst the moderate/severe group. This is in line with the findings of others [17,31]. However, approximately 20% of parents of mildly injured children reported changes in personality, concentration, and schoolwork. Parents of children in both severity groups reported an increase in the number of arguments with siblings since the injury. Children with mild brain injuries were unlikely to suffer problems with mobility (approximately 5%) compared with those with more severe injuries (approximately 20%). However, 10% of the mild group had visual problems and difficulties with sleeping after the injury compared to 20% of moderate/severe group.

Although those with mild injuries had fewer problems, nearly one third of their parents took advantage of our offer of discussing issues with our Brain Injury Nurse Adviser, indicating that parents remained concerned about the effects of the injury.

The siblings of an injured child were more affected if their brother or sister had suffered a severe or moderate brain injury. This was most evident in the first few months following the injury. This effect was particularly apparent for siblings who witnessed the accident. It is notable that a small number of siblings had been diagnosed with post traumatic stress disorder. Some older siblings experienced guilt if they felt in some way responsible for the injury, for example if they were with the injured child at the time. One parent wrote: '*X (sibling) suffered stress and became withdrawn and felt that the accident was his fault, as he went out and then Y (injured child) followed him into the road and was hit by a car.*' Some parents commented that they had not considered the effect that witnessing the TBI may have had on brothers or sisters. A parent wrote: '*his sister was very worried about him. We*

overlooked how it affected her, she was there all through the accident, and ambulance arriving etc. She was only 4. She still remembers it vividly.' It is known that a TBI can affect the whole family [34], and with the immediate trauma of the injured child being admitted to hospital, the effect on siblings can be underestimated. Therefore parents should be given information on the possible effects a TBI may have on siblings, and advised when to seek professional help and support.

Summary and implications

Brain injury in children can have long-lasting and wide-ranging sequelae. However, only 30% of the participants received clinical follow-up after hospital discharge. Even in the severe group nearly one quarter did not have clinical follow-up. Another important finding of this study was the lack of therapeutic or rehabilitative input received by children after a moderate or severe brain injury. It was notable that children with moderate brain injury were a particularly neglected group, only two thirds of their parents received information, only half of them had a clinical follow-up, and 14% received therapy. Although on average they each missed a month of school, only one third of schools made any special provision for their return to education.

Most children do not visit their family doctor more frequently following a brain injury. This may be because problems are frequently cognitive and psychological rather than physical.

Schools rely on parents informing them about the child's brain injury and are unlikely to have any information on the consequences of such an injury. Therefore, it is unsurprising that most schools failed to make special arrangements for a child's return to education. It is recommended that when a child is admitted to hospital following a serious TBI, hospital staff inform the head teacher of the child's school, and provide a list of possible symptoms to look out for.

One third of parents of moderately or severely injured children and one quarter of parents of mildly injured children did not receive information on brain injury or what to expect. Consistent information on both short-term and long-term symptoms following TBI should be routinely given to all parents of a child admitted to hospital with a brain injury, both verbally and in writing. Parents should also be given the opportunity to discuss their concerns with a knowledgeable health professional, such as a brain injury nurse adviser. All children admitted with a TBI should be offered a clinical follow-up. In North Staffordshire all adults admitted with TBI are offered a follow-up appointment at a brain injury clinic run by a dedicated brain injury nurse and an assistant psychologist. It is recommended that this service be extended to include children with TBI.

Possible limitations of the research

The response rate of 56.2% is highly acceptable and in line with the response rate of 57.4% achieved in a recent population-based survey of 909 brain injured adults in the United States[22]. However, it was not possible to follow up 43.8% of children admitted with a brain injury. It may be argued that our respondents were a self-selecting group – as they chose to respond. However, we received many completed questionnaires from parents who had not noticed problems, which indicates that the sample is probably representative of the whole population of brain injured children. In the mild group, a large proportion of parents reported

few or no problems, and some of parents in the moderate and severe groups reported few problems.

Changes in the child since injury rely on parental report; however, a child's admission to hospital is a memorable event for most parents and therefore reports are likely to be reliable. The children in the study were injured at different times post-injury, and it is possible that parents of children injured several years before the study were unable to accurately recall what the child was like before the TBI. However, no differences in symptom reporting were observed when the data was analysed by time since injury.

A study of this nature can only be observational and descriptive, as although symptoms related to TBI were reported by parents, it was not possible to determine whether they were actually caused by the TBI.

Unanswered questions and future research

This research studied the population covered by North Staffordshire Regional Health Authority. This includes rural, semi-rural, and inner-city areas, so should be reasonably representative of other populations of children in the UK. However, a prospective national study, using similar techniques, should be carried out to ascertain the nature of outcomes following paediatric TBI for other areas of the UK.

Further research needs to be carried out to evaluate the effectiveness of a brain injury clinic for children following TBI.

A sub-group of respondents to the postal questionnaire have now been interviewed and assessed using a range of measures, and compared with a control group of non-injured children. The findings will be reported in the near future.

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Contributors:

CAH led the study, analysed the data and interpreted the results. ABW had the idea of the brain injury register and created the post of brain injury nurse. JL was the brain injury nurse responsible for maintaining the register and advising parents. ARM advised on the content of the questionnaire and assisted with the pilot study.

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Table 1: Definitions of Injury Severity

Severity of Traumaic Brain Injury	Definition
Mild	An injury causing unconsciousness for less than 15 minutes and a GCS after initial resuscitation of 13-15
Moderate	An injury causing unconsciousness for more than 15 minutes and a GCS after initial resuscitation of 9-12
Severe	An injury causing unconsciousness for more than 6 hours and a GCS after initial resuscitation of 3-8

Table 2 Follow-up and information received

	MILD N = 419 Number (percent)	MODERATE N = 57 Number (percent)	SEVERE N = 49 Number (percent)
Received follow-up Appointment	91 (21.7)	29 (50.9)	38 (77.6)
Received therapy	14 (3.3)	8 (14)	18 (36.7)
Information received	323 (77.1)	36 (63.2)	31 (63.3)
Found information Useful	306 (73)	34 (59.6)	26 (53.1)
Accident prevention advice received	58 (13.8)	5 (8.8)	7 (14.3)
Found advice useful	52 (12.4)	5 (8.8)	7 (14.3)
Unmet information requirements	32 (7.6)	13 (22.8)	14 (28.6)

Table 3

Frequency of visits to General Practitioner before and after head injury

Frequency of visits to GP	MILD BEFORE HI N = 370 Number (%)	MILD AFTER HI N = 370 Number (%)	MODERATE/ SEVERE BEFORE HI N = 102 Number (%)	MODERATE/ SEVERE AFTER HI = 102 Number (%)	ALL BEFORE HI N = 472 Number (%)
Never	19 (5.1)	69 (18.6)	4 (3.9)	16 (15.7)	23 (4.9)
Rarely	145 (39.2)	89 (24.1)	44 (43.1)	15 (14.7)	189 (40.0)
Occasionally (1-3 times/year)	153 (41.4)	169 (45.7)	42 (41.8)	51 (50)	195 (41.3)
Frequent (4 or more times/year)	51 (13.8)	41 (11.1)	12 (11.8)	16 (15.7)	63 (13.3)
Don't know	2 (0.5)	2 (0.5)	0	1 (1.0)	2 (0.4)
N/A (still in rehab. unit)	0	0	0	3 (2.9)	0

Table 4 Parental reports of changes in the child since the brain injury (n = 521). Chi Squared Cross-tabulations identifying differences in 'yes' responses between the mild group and the moderate/severe group

Changes since the brain injury	MILD N = 411 Number (percent)	MODERATE/SEVERE N = 110 Number (percent)	SIGNIFICANCE LEVEL (df=1)
Personality Change	83 (20.2)	62 (56.4)	P = 0.001 $X^2 = 56.52$
Change in Sense of Humour	45 (10.9)	32 (29.1)	P = 0.001 $X^2 = 22.68$
More introverted	34 (8.3)	23 (20.9)	P = 0.001 $X^2 = 14.22$
More extroverted	53 (12.9)	26 (23.6)	P = 0.005 $X^2 = 7.78$
Problems keeping up with schoolwork	79 (19.2)	35 (31.8)	P = 0.004 $X^2 = 8.06$
Getting into trouble at school	64 (15.6)	20 (18.2)	P = 0.5 NS $X^2 = 0.48$
Poor concentration	99 (24.1)	57 (51.8)	P = 0.001 $X^2 = 31.81$
Memory problems	52 (12.7)	43 (39.1)	P = 0.001 $X^2 = 40.68$
Has fewer friends	34 (8.3)	22 (20)	P = 0.001 $X^2 = 12.4$
Has more friends	73 (17.8)	21 (19.1)	P = 0.7 NS $X^2 = 0.1$
Is less sociable	44 (10.7)	25 (22.7)	P = 0.001 $X^2 = 10.92$
Is more sociable	82 (20)	25 (22.7)	P = 0.5 NS $X^2 = 4.2$
Is more active	65 (15.8)	22 (20)	P = 0.3 NS $X^2 = 1.09$
Is less active	39 (9.5)	25 (22.7)	P = 0.001 $X^2 = 14.11$
More arguments with siblings*	109 (34.7)	50 (54.9)	P = 0.001 $X^2 = 12.11$
Fewer arguments with siblings*	16 (5.1)	3 (3.3)	P = 0.5 NS $X^2 = 0.51$
Problems with balance and co-ordination	22 (5.4)	23 (20.9)	P = 0.001 $X^2 = 26.61$
Difficulties walking	10 (2.4)	16 (14.5)	P = 0.001 $X^2 = 26.85$
Difficulties running	20 (4.9)	22 (20)	P = 0.001 $X^2 = 26.82$
Difficulties sleeping	43 (10.5)	22 (20)	P = 0.008 $X^2 = 7.22$
Visual problems	43 (10.5)	24 (21.8)	P = 0.002 $X^2 = 9.99$
Hearing problems	25 (6.1)	13 (11.8)	P = 0.04 $X^2 = 4.22$
Change in appetite	41 (10)	29 (26.4)	P = 0.001 $X^2 = 20.04$
Change in food preferences	31 (7.5)	20 (18.2)	P = 0.001 $X^2 = 11.12$
Problems with temperature control	20 (4.9)	20 (18.2)	P = 0.001 $X^2 = 21.71$
Change in hand dominance	5 (1.2)	5 (4.5)	P = 0.02 $X^2 = 5.11$

* number of children with siblings responding = 408