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# Title: REPORTED PROBLEMS AND THEIR RESOLUTION FOLLOWING MILD, MODERATE AND SEVERE TRAUMATIC BRAIN INJURY AMONGST CHILDREN AND ADOLESCENTS IN THE UK

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## **Abstract**

The families of 97 children with mild (49), moderate (19) and severe (29) traumatic brain injury (TBI), aged 5–15 at injury, were interviewed and assessed at a mean of 2.29 years postinjury and compared with 31 healthy controls. Following the TBI, 83 (85.6%) had no therapeutic input, 74 families (76.3%) had unmet information needs, particularly regarding long-term consequences. At first interview 1097 problems were reported by the TBI group. Behavioural and school problems were frequently reported by all TBI groups, significantly more than controls (p  $\leq$  0.001). On the Vineland Adaptive Behaviour Scales 63% of mild and 70% of severe TBI groups demonstrated significant maladaptive behaviour. Children in the mild and moderate/severe groups were significantly more anxious than controls on the HADS (p  $\leq$  0.05). At 12 month follow-up there were no significant differences in problem resolution between the TBI groups, 498 (53.9%) problems remained unchanged and 75 (8.1%) had worsened.

#### Introduction

Traumatic brain injury (TBI) is a leading cause of mortality or permanent disability in children and adolescents [1,2]. Estimates of the incidence of paediatric brain injury vary, ranging from 180/100,000 [3] to over 300/100,000 [4,5]. Approximately 81% of these brain injuries will be mild, 5% fatal, 6% severe and 8% moderate [6]. For survivors it is likely that there will be intellectual, academic and personality adjustment problems [7]. In a review of the literature, Taylor and Alden [8] concluded that the sequelae of childhood brain injury either remains relatively constant over time post-injury or worsens. Consequently there are thousands of children and adolescents currently in the community living with the long-term consequences of their brain injury, in all likelihood without the benefit of professional help or support.

Many studies suggest a link between severity of injury and cognitive deficits [9]. Furthermore, post-traumatic cognitive and behavioural problems following moderate and severe head injury amongst children are persistent and often evolve over time [10]. There is an assumption, however, that most children with mild TBI will make a good recovery [11]. Furthermore, some studies use children with mild TBI as 'controls' for children with severe TBI [12]. There have been a number of studies of mild TBI which provide conflicting results, and likely outcomes following mild TBI remain unclear [13]. However, the term 'mild' TBI can be ambiguous, some studies include patients attending Accident and Emergency departments who return directly to home after treatment, whereas others recruit patients who have been admitted to hospital for neurological observation. Asarnow *et al* [14] have highlighted the lack of a consensus on the definition of mild TBI, and the possible effect this has had on research findings.

There have been a limited number of long-term follow-up studies of children after brain injury. The most notable of these is probably that of Klonoff and colleagues who have followed a prospective group of children with TBI through to adulthood [15]. The majority of these children had suffered a mild TBI, with approximately 10% of the group having suffered a moderate or severe TBI. At 23 year follow-up 31% of the sample reported subjective sequelae. This study illustrates that symptoms can be very enduring even after mild TBI.

There have been very few controlled studies which examine in detail the problems that children have following hospital admission with mild, moderate, and severe TBI, and which systematically examine these problems by age and time since injury. Therefore, the study described here has the following primary objectives:

- To examine the patterns of problem reporting by families following mild, moderate and severe TBI, and how these differ from problems reported by control families.
- 2 To identify these problems, and determine whether they differ according to the age of the child when reported, and time elapsed since injury.
- To identify problems which are reported spontaneously by parent and injured child
- 4 To compare reported problems with assessment of maladaptive behaviour
- 5 To identify those problems most likely to resolve over time
- 6. To examine information and follow-up requirements

#### Methods

#### Study Population

In 1998 a postal questionnaire was sent to parents of all 974 surviving children admitted for ≥24 hours to North Staffordshire Hospitals NHS Trust with TBI between November 1992 and December 1998 who were aged 5-15 years at the time of the injury. Patients were identified retrospectively from 1992 – 1997, and prospectively from January to December 1998. Five hundred and twenty-five parents completed and returned the questionnaire. The children of all respondents were living in the community. Injury severity was determined using Glasgow Coma Scale (GCS) [16] scores where recorded and/or duration of loss of consciousness. Using the British Society of Rehabilitation Medicine classification of severity [4] (Table 1) 49 (9.3%) of the group had severe brain injuries, 57 (10.9%) moderate, and 419 (79.8%) mild.

#### Table 1 about here

At the end of the questionnaire parents were invited to participate in an interview study, and over one quarter of parents (139, 26.5%) volunteered to take part. Of these 90 had children with mild TBI, 19 moderate TBI, 29 severe TBI, and 12 with unspecified injury severity but a long in-patient stay. We had aimed to recruit 30 children with severe TBI, 30 moderate TBI and 30 mild TBI, in order to compare groups. Consequently all of the volunteers with moderate and severe TBI were recruited to the interview study. The mild group was recruited to match the moderate and severe groups in terms of age, sex, and time since injury. The interview group was made up of 97 young people with TBI. Table 2 shows the number of children in each severity category during the three phases of the study. For the first and second interviews the proportion of children within each severity grouping remained constant at approximately 50% mild injuries, 20% moderate injuries, and 30% severe injuries.

Table 2 about here.

## Control group

At the interview with the family of the brain injured child, the family was asked to suggest a child of the same age, sex, and social background and in the same school class as the injured child to act as a control. Sixty-two families were able to identify a control child. Thirty-one control children agreed to participate in the study, none had a history of head injury. This formed a control group of similar size to each of the TBI groups, with approximately the same age profile (shown in table 3). The control children and parents were interviewed and assessed in their own homes by psychology assistants.

#### Measures

Information on problems and difficulties were collected using a structured questionnaire developed for the study. At the beginning of each interview parents and the injured child were asked what main difficulties, problems or behaviours concerned them at that time. Following these spontaneously reported problems the interviewer proceeded to prompt the respondents using a list of possible problem categories, these were recorded separately. Areas covered were behaviour, emotion, cognition, physical problems, mobility, schoolwork, school problems, social integration, leisure activities, and employment if any. The list of prompted categories is reproduced in Appendix I. Parents were also asked about their information needs, and the services they had received from health, social and education agencies.

The Hospital Anxiety and Depression Scale (HADS) [17] was administered to children aged 11 years and above at the time of interview 1. This is a questionnaire designed to detect anxiety and depression in general medical outpatient populations, including community patients. Items are rated on a four-point scale ranging from absence of a symptom to maximum symptomatology. The scale provides a score for both anxiety and depression. The clinical significance of anxiety or depression is calculated on a scale whereby scores of 0-7 are non cases, 8-10 are borderline cases, and scores of 11-21 indicate clients whose condition merits psychiatric assessment [17].

The Vineland Adaptive Behaviour Scales (VABS) Interview Edition, Survey Form [18] were used to assess adaptive behaviour, in particular maladaptive behaviours, amongst children with TBI and controls. All assessments were carried out by trained clinical psychology graduates under the supervision of a consultant clinical neuropsychologist. Raw scores on the Maladaptive Behaviour Domain were converted into age-adjusted maladaptive levels of 'non-significant', 'intermediate', and 'significant' according to published norms.

The Problem Resolution Scale (PRS), developed to measure changes over time in a UK national study of adults following TBI was used [19, 20]. This scale monitors changes in reported problems over time on a five point scale where 1 = completely recovered, 2 = almost completely recovered, 3 = improved but still significant, 4 = stayed the same, and 5 = got worse.

#### **Procedure**

The initial interviews and assessments took place between October 1998 and April 1999. Ninety-seven children and their families were interviewed face-to-face in their own homes by highly experienced interviewers. The interviews took place as soon as possible after the postal questionnaire was returned, and informed written consent obtained from the parent, and for children over the age of 13 from the child him/herself. Initial interviews with control families took place between November 1998 and June 1999.

## Follow-up

Twelve months after the first interview each child and his/her parents were offered a further interview and assessment. The second interviews took place between October 1999 and May 2000. At the follow-up interview problems reported at first interview were revisited and scored on the Problem Resolution Scale according to whether they had resolved, improved, stayed the same or worsened. Any new problems or concerns were recorded. The VABS and HADS were readministered.

Control children were also contacted twelve months later. Two thirds of children (21) and their parents agreed to participate in the follow-up interviews and assessments.

# Statistical analyses

Descriptive statistics including means and standard deviations were calculated for continuous variables. Where appropriate analysis of variance (ANOVA) procedures were used to compare means. Cross-tabulations were carried out on categorical data and the Pearson Chi-Square statistic calculated, all using SPSS Version 9.0.

#### **Results**

#### **Participants**

Of the 97 children in the interview group two thirds (64, 66%) were male. Forty-nine children had suffered a mild TBI, 19 moderate, and 29 severe. At the time of the injury the participants were aged between 5 and 15 years. The mean age was 9.85, SD = 3.12. Table 3 shows demographic characteristics for each severity group and the control group.

Table 3 about here.

*Interval between injury and first interview* 

Participants were interviewed between 6 months and 5 years post injury. The mean interval between injury and interview was 2.29 years, SD = 3.53. Fifteen subjects (11.7%) were less than 1 year post injury at the time of the first interview. When divided into sub-groups by injury severity the number of subjects  $\le 1$  year post injury in each group was too small for statistical analysis. Therefore when analysing data by time since injury groups were divided into less than 2 years (n = 31) and  $\ge 2$  years (n = 66) post injury.

#### **Ethnicity**

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 [21]. This was reflected by our respondents, 99% of whom were white.

# Deprivation

Social deprivation was measured using Townsend Deprivation Scores [22] which were calculated using postcodes. Valid postcodes were available for 94 families in the TBI group. The higher the positive score the more deprived an area, and the higher the negative score the more prosperous. The mean score was +1.24, SD = 2.84, with a range of -5.14 to +8.29. Compared to the national average of zero our group came from more deprived areas. Two thirds (63, 67%) of families lived in areas with positive scores. Sixteen families (17%) lived in considerably deprived areas (scores of +3.55 and above), whereas 14 families (14.9%) lived in more affluent areas (scores of -2.4 and below).

In the control group valid postcodes were available for 27 families. The mean score was -0.16, SD = 2.69, with a range of -4.93 to +5.1. Almost two thirds (17, 63%) of families lived in areas with positive scores. Three families (11.1%) lived in considerably deprived areas (scores of +3.55 and above), whereas 8 families (29.6%) lived in more affluent areas (scores of -2.4 and below).

# Mechanism of Injury

The most common causes of brain injury were road traffic accidents (44, 45.4%), especially as pedestrians (31, 32%), and falls (28, 28.9%). All causes are shown in table 3. Those with a mild TBI were most likely to be injured by a fall, whereas those with a severe TBI were most likely to be injured as a pedestrian in a road accident.

#### Accident Prone Children

Parents were asked if they would describe their child as 'accident prone' before the TBI, 21 parents (21.6%) agreed, representing one quarter of the parents in the mild group, nearly one third of those in the moderate group, and 10% of the severe group.

#### Other injuries

Fifty-four children had suffered other injuries at the time of the brain injury, representing 55.7% of the sample. These were either serious such as fractures to arms, legs, or pelvis; broken legs or wrists; chest injuries; or facial injuries (30 children), or minor such as cuts, grazes and bruises (24 children). In the mild group 26 children (53.1%) had suffered other injuries, 11 of them serious (22.4%). In the moderate group 6 children (31.6%) suffered other injuries, 2 of them serious (10.5%), and in the severe group 22 children (75.9%) suffered other injuries, 16 of these serious (55.2%).

At the time of the survey these other injuries were still giving problems for 31 (32%) of the TBI group. These injuries remained a problem for 17 (34.7%) of the mild group, 5 (26.3%) of the moderate group, and 9 (31%) of the severe group.

## Therapeutic input

Following the TBI, four children had received comprehensive rehabilitation, all were in the severe TBI group. A further seven children in the severe group had received only physiotherapy. One child with severe TBI and one with moderate TBI had received only psychological input, and one child with moderate TBI had been referred to a psychiatrist for behavioural problems. At the time of the first interview three children, all with severe TBI, were continuing to receive therapy, one receiving multi-disciplinary rehabilitation, one physiotherapy only, and one psychology only.

# Age at time of first interview

All children recruited to the study were aged between 5 and 15 years at the time of the brain injury. However, some of the injuries took place up to 5 years before the start of the study. At first interview subjects ranged from age 6 to 20, with a mean age of 13.13 years, SD = 3.53. Previous researchers have grouped children into two age groups, usually dividing them around the age of 10-11 years [23,24]. As 11 is the age when most children progress from junior to secondary education we divided our subjects into groups of 5-10 year olds and 11-20 year olds at time of first interview for analytical purposes.

# Number of problems reported

For the 97 families in the TBI group a total of 1097 problems were reported, an average of 11.31 problems per family (SD=6.54). Respondents were classified according to injury severity, and were compared with control children. The severe TBI group reported the most problems, with a mean of 15.2 problems per family (SD=6.31). The moderate TBI group reported a mean of 10.95 problems per family (SD=6.39), and the mild TBI group reported a mean of 9.1 problems per family (SD=5.74). For control children the mean was only 5.6 problems per family (SD=4.76). Comparison of means using an Analysis of Variance (ANOVA) of the 'Group' X 'Number of Problems at Interview 1' found a strong statistically significant difference between the mild, moderate/severe and control groups (F = 17.87, df = 2, p = 0.0001).

The number of reported problems was further analysed by comparing children aged 10 years or younger with children aged 11 years or older at the time of the first interview. Children with TBI were grouped by injury severity. Children with moderate or severe TBI were grouped together as otherwise the numbers would be too small for meaningful comparisons. Table 4 gives the number, mean and SD of problems reported by each group.

#### Table 4 about here.

Comparison of means using an ANOVA of the 'Group' X 'Number of Problems at Interview 1', divided by age group, found significant differences in the number of problems reported between the groups. For ages 10 years and under there was a significant difference in problem reporting between mild, moderate/severe and control groups (F = 4.85, df = 2, p = 0.015), between moderate/severe and control groups (F = 6.24, df = 1, p = 0.022), and between mild and moderate/severe groups (F = 7.59, df = 1, p = 0.011). There was no difference between the mild and control groups (F = 0.23, df = 1, p = 0.64).

For ages 11 years and over there was a significant difference between mild, moderate/severe and control groups (F = 13.30, df = 2, p = 0.0001), between moderate/severe and control groups (F = 26.56, df = 1, p = 0.0001), between mild and moderate/severe groups (F = 6.60, df = 1, p = 0.012), and between the mild and control groups (F = 8.61, df = 1, p = 0.005).

# Most frequently reported problems

The most frequently reported problems were compared for the three severity groups and the control group and are shown in Table 5. The problems most frequently reported by the TBI groups were headaches, mood fluctuations, concentration, temper, memory, attitude towards siblings, behaviour, tiredness, schoolwork, learning, and lost friendships. For the control group the most frequently reported problems were mood fluctuations, headaches, and concentration.

#### Table 5 about here

The Chi Squared statistic was used to measure differences in the frequency of problem reporting between controls and injured children. Firstly controls were compared with moderate and severely injured children. There were significant differences between the injured and non-injured children for 13 problem items, as shown in table 6. In all cases more injured than non-injured children reported these problems, most significantly behavioural and family problems. More injured children had problems with schoolwork but this did not quite reach significance at the 5% level.

#### Table 6 about here.

Secondly, controls were compared with mildly injured children. Seven problem items were reported significantly more frequently by injured children than controls, as shown in table 7. Again, the most highly significant difference was found with behavioural problems, with far more injured children reporting these than controls.

#### Table 7 about here.

Regardless of severity, children with TBI demonstrated behaviour, temper and school problems more frequently than control children, a finding significant at the 1% level ( $p \le 0.01$ ).

Thirdly, children in the mild TBI group were compared with children in the moderate/severe TBI group. There were significant differences for only four problem items, shown in table 8. Those in the moderate/severe group were more likely to report family problems, problems with compensation, friendships and sleep.

#### Table 8 about here.

## The effect of age on problems reported

In order to determine whether different age groups reported different problems, children with TBI and controls were divided into two age groups, age 10 and under (TBI: n=27, control: n=7), and age 11 and over (TBI: n=70, control: n=24) at the time of the first interview.

Most problems were reported fairly equally by both age groups. In the TBI group there were significant differences between older and younger children in the frequency of problem reporting for three items. These were temper ( $\leq 10 \text{ yrs} = 77.8\%$ ,  $\geq 11 \text{ yrs} = 55.7\%$ ,  $X^2 = 4.51$ , p = 0.034), schoolwork ( $\leq 10 \text{ yrs} = 55.6\%$ ,  $\geq 11 \text{ yrs} = 27.7\%$ ,  $X^2 = 6.91$ , p = 0.009), and being bullied ( $\leq 10 \text{ yrs} = 18.5\%$ ,  $\geq 11 \text{ yrs} = 5.7\%$ ,  $X^2 = 3.80$ , p = 0.051). In all three cases younger children were more likely to have these problems.

In the control group there were significant differences between older and younger children in the frequency of problem reporting for two items. These were schoolwork ( $\leq 10 \text{ yrs} = 42.9\%$ ,  $\geq 11 \text{ yrs} = 9.5\%$ ,  $X^2 = 4.78$ , p = 0.029) and learning ( $\leq 10 \text{ yrs} = 42.9\%$ ,  $\geq 11 \text{ yrs} = 0\%$ ,  $X^2 = 11.39$ , P = 0.001). Younger children were more likely to have these problems.

# The effect of time since injury on problems reported

The frequency of problem reporting was also analysed by severity and time since injury. Respondents were divided in to four groups: a) mild, <2 years post injury: n=15, b) mild,  $\geq$ 2 years at the time of first interview: n=34, c) moderate/severe, <2 years post injury: n=16, and d) moderate/severe  $\geq$ 2 years at the time of first interview: n=32. Table 9 gives details. The Chi Squared statistic was calculated for each individual problem item. In the mild group there was a tendency for most problems to be reported more frequently by the more recently injured sub-group. However there was a statistically significant difference between the <2 years and  $\geq$ 2 years sub-groups for only one item, lack of clinical follow-up post injury (<2 yrs =40%,  $\geq$ 2 yrs = 11.8%,  $X^2$  = 5.11, p = 0.024). Differences between the time-since-injury groups nearly reached significance for the category of 'friendships' comprising problems of lost friends and difficulties in making new friends (<2 yrs =33.3%,  $\geq$ 2 yrs = 11.8,  $X^2$  = 3.23, p = 0.072).

#### Table 9 about here.

In the moderate/severe group there were no significant differences between the sub-groups for any problem item. However, seventeen problem items were reported more often by those <2 years post-injury. These were anxiety, attitude to siblings, behaviour, being bullied, clumsiness, compensation, family problems, lost hobbies, mobility, mood fluctuations, nightmares, personality change, school behaviour, unsympathetic school, sleep, speech, and temper.

#### *Unprompted problems*

At the beginning of each interview parents and the child were asked what main difficulties, problems or behaviours concerned them at that time. Twenty-nine separate problems were reported spontaneously. Ten parents in the mild group and seven parents in the moderate/severe group did not report any problems spontaneously. Fifty children did not report any problems spontaneously. Twenty-seven were aged  $\leq 10$  years and too young to comprehend the question. The most frequently reported problems are shown in table 10 grouped by injury severity and respondent. Headache was the problem most frequently reported by the child themselves, particularly in the mild group (16, 32.7%). It was also the most common problem spontaneously reported by parents (24, 24.7%). The child's behaviour was a major concern for 9 parents (18.4%) in the mild group and 10 (20.8%) in the moderate/severe group. Physical and emotional problems tended to be spontaneously reported more frequently than intellectual problems. There were no significant differences between the

mild and moderate/severe groups except for the reporting of intellectual problems ( $X^2 = 4.62$ , p = 0.03, df = 1).

Table 10 about here.

#### Maladaptive behaviour at first interview

The Vineland Adaptive Behaviour Scales (VABS) were used to assess maladaptive behaviours amongst both injured (n = 63) and control (n = 10) children. Raw scores were converted into age adjusted levels of 'significant', 'intermediate' and 'non-significant' maladaptive behaviour. The maladaptive behaviour levels are shown in table 11 for children in each severity category and controls. A significant difference in maladaptive behaviour levels was observed between the TBI and control groups ( $X^2 = 12.32$ , p = 0.002, df = 2). Injured children demonstrated much higher levels of maladaptive behaviour. There were no significant differences between mild, moderate and severe TBI groups ( $X^2 = 2.23$ , P = 0.69, P = 0.6

#### Table 11 about here.

Maladaptive behaviour levels were compared with the number of problems reported by parents at interview, and a significant correlation obtained (Spearman's rho = 0.64, p = 0.01 (2-tailed)). There was a particularly strong association between number of problems and 'significant' maladaptive behaviour, 90.9% of children (30) demonstrating 'significant' maladaptive behaviour had thirteen or more problems at interview. Furthermore, 90% of children described by their parents as having behavioural problems scored at the 'significant' maladaptive behaviour level on the VABS.

## Anxiety and depression at first interview

The Hospital Anxiety and Depression Scale (HADS) was used to assess children over the age of 11 years at the time of first interview. In the TBI group 35 children with mild TBI and 32 children with moderate or severe TBI were assessed. In the control group 14 children were assessed. Subjects were divided into cases (scores 11-21), borderline cases (scores 8-10) and non-cases (scores 0-7) for anxiety and depression. Table 12 shows the results. For Anxiety 50% of respondents in the moderate/severe group were either 'cases' or 'borderline cases', in the mild group 42.9% were 'cases' or 'borderline cases'. There was only one 'case' in the control group. Few children were depressed, the only 'cases' were in the moderate/severe group (4, 12.5%).

#### Table 12 about here.

Cross tabulations were carried out to compare the three case types between the control, mild TBI and moderate/severe TBI groups. There were significant differences between the three groups for anxiety ( $X^2 = 9.89$ , p = 0.042, df = 4), but not for depression ( $X^2 = 6.91$ , p = 0.14,. df = 4). For anxiety there were significant differences between the control and moderate/severe groups ( $X^2 = 7.87$ , p = 0.02, df = 2), and between the control and mild groups ( $X^2 = 6.31$ , p = 0.04, df = 2), but not between the mild and moderate/severe groups ( $X^2 = 4.77$ , p = 0.09, df = 2).

#### *Information and follow-up requirements*

At first interview parents were asked what information they had received from clinical staff at hospital discharge, and what information they required which would help them and other families who have a child with a brain injury.

Of the 49 families of a child with a mild TBI 35 (71.4%) had specific information requirements that were not met. Twenty-two families (44.9%) required more advice on long-term consequences of a brain injury. Eight (16.3%) would have liked some follow-up from the hospital, and four (8.2%) required additional support following the injury, for example counselling and family support.

Of the 19 families of a child with a moderate TBI 15 (79%) had specific information requirements that were not met. Fourteen families (73.6%) required more advice on long-term consequences and where to seek help. Six families (31.6%) would have liked some hospital follow-up, and four (21%) required family support.

Of the 29 families of a child with a severe TBI 24 (82.8%) had further information requirements. Twenty families (69%) required further advice on possible long term consequences of the injury. Fifteen families (51.7%) required support, for example counselling, someone to talk to, or to be put in contact with a support group. Ten families (34.5%) had received no follow-up but needed it, and four families (13.8%) said that the child needed rehabilitation but had not received any. The parents of three children purchased private rehabilitation for their child.

## Number of problems which resolve

In the TBI group 86 families were followed-up and interviewed twelve months later. During the interval between first and second interviews only two families had received any therapeutic intervention from health professionals. At the second interview each of the previously reported problems were discussed and, using the PRS categories, the family asked if the problems had completely recovered, almost completely recovered, improved, stayed the same or worsened. Nine hundred and twenty four problems were revisited at second interview. Analysis of the problems database showed that at follow-up 134 (14.5%) problems had completely recovered, 90 (9.7%) had almost completely recovered, 127 (13.7%) had improved but were still significant, 498 (53.9%) had stayed the same, and 75 (8.1%) had got worse.

Table 13 shows the categories of problem resolution for each severity group and controls. In the mild group a higher proportion of problems had completely resolved at follow-up (19.9%) compared to the moderate and severe groups (11.9% and 10.9%). Also in the mild group fewer problems stayed the same (43.6%) compared to the moderate (64.5%) and severe (58.3%) groups. There were no statistically significant differences between the groups.

Twenty-one control children agreed to the follow-up interview. One hundred and five problems were revisited, 30 (34.9%) problems had completely recovered, 48 (45.3%) remained the same, and 4 (3.8%) had worsened.

Table 13 about here.

Problem resolution was also analysed by time since injury, but showed very little variation. For problems reported <2 years after injury 417 problems were revisited, 53 (12.7%) had completely resolved, 229 (54.9%) stayed the same, and 27 (6.5%) got worse. For problems reported  $\geq$ 2 years after injury 501 problems were revisited, 79 (15.8%) had completely resolved, 268 (53.5%) stayed the same, and 47 (8.4%) got worse.

# Type of problems which resolve

Each problem item was analysed to identify those problems which had completely resolved at follow-up and those which had stayed the same or worsened. These problems were further analysed by injury severity. Table 14 gives details. In the mild group the problems which tended to resolve in over 50% of cases were clumsiness, physical problems, mobility, speech, hearing, and being bullied. In the moderate/severe group none of the problems had resolved for over 50% of cases. Those problems most likely to resolve were sleep (33.3%) and epilepsy (33.3%). Most problems stayed the same or worsened.

#### Table 14 about here.

In the mild group the most persistent problems, the same or worse for over 50% of of those originally reporting the problem, were attitude to siblings, compensation, follow-up, information needs, lost hobbies, nightmares, personality change, and temper. For the moderate/severe group 25 problem items had stayed the same or worsened for over half of those originally reporting the problem. The most enduring problems, remaining or worsening for over two thirds of respondents, were attitude to siblings, clumsiness, compensation, concentration, follow-up, hearing, information needs, lost hobbies and activities, mobility, mood fluctuations, physical problems, schoolwork, school behaviour problems, general school problems, unsympathetic schools, and temper.

## New problems at follow-up

Of the 86 families followed up in the TBI group, 16 parents (18.6%) reported no new problems. A wide range of new problems were reported by the remaining 70 families. The most frequently reported new problems were temper (12, 17.1%), attitude (11, 15.7%), schoolwork (8, 11.4%), concentration (7, 10%), behaviour (7, 10%), physical problems (6, 8.6%), reading and writing (5, 7.1%), aggression (5, 7.1%), moods (5, 7.1%), and motivation (4, 5.7%).

In the control group 21 families were interviewed one year after the first interview. Only 5 parents (23.8%) reported new problems. These were attention, concentration, schoolwork, and for two children stress due to parental divorce.

# Maladaptive behaviour at follow-up

The VABS were used to assess maladaptive behaviours for 86 injured and 20 control children at second interview. These numbers were higher than previously, as unavoidably not all children were assessed on VABS at first interview. The maladaptive behaviour levels are shown in table 11. Far from improving, maladaptive behaviours amongst the TBI group were even more apparent. A highly significant difference in maladaptive behaviour levels was observed between the TBI and control groups ( $X^2 = 21.0$ , p = 0.0001, df = 2). Importantly, 61.6% of injured children demonstrated 'significant' maladaptive behaviour compared to 5% of controls. There were no significant differences between the mild, moderate and severe TBI

groups ( $X^2 = 2.07$ , p = 0.72, df = 4). Even in the mild group 25 children (56.8%) demonstrated 'significant' maladaptive behaviour.

Anxiety and depression at follow-up

Follow-up assessments were carried out with children who had been aged 11 years or over at the time of first interview. In the TBI group 26 children with mild TBI and 26 children with moderate or severe TBI were assessed. In the control group 11 children were assessed. Subjects were divided into cases, borderline cases, and non-cases for anxiety and depression. The results are shown in table 12. The results were very similar to those obtained at first interview. For Anxiety three children in the control group were 'cases', the parents of two of these were going through divorce which may have influenced this result.

Cross tabulations were carried out to compare the three case types between the control, mild TBI and moderate/severe TBI groups. There were no significant differences between the three groups for either anxiety or depression.

#### **Discussion**

This study has demonstrated that children with TBI continue to suffer the consequences of their brain injury long after the initial trauma. The more severe the TBI the greater the number of problems reported. However, the study has provided evidence to show that even children with mild TBI can have varied and persistent problems following the injury. Children with mild TBI reported twice as many problems as control children, and there were no significant differences in problem resolution between mild, moderate and severe TBI. Approximately two thirds of children in all three TBI groups had significant maladaptive behaviours, as measured on the VABS.

Very few of our subjects had received any therapeutic intervention following their injury. The majority were discharged home without adequate follow-up or support. Even in the severe group one third of families reported that they had not received clinical follow-up. Only four children in the entire TBI group had received multi-disciplinary rehabilitation, and for three the rehabilitation was privately funded. It is, therefore, perhaps unsurprising that so many problems were reported at first interview.

We found that over 70% of families, regardless of injury severity, had unmet information needs, a finding consistent with other studies [25]. Many required more advice on long-term consequences of the injury, especially the parents of children with moderate and severe head injuries. Several of the parents in the severe group reported that although some information may have been given verbally whilst their child was in hospital, they had not taken it in. Written information was described as more useful as it could be referred to later, when parents were ready to absorb the information.

Two thirds of the children in the TBI group came from areas with an element of social deprivation, 17% from very deprived areas. Several other authors have also observed a link between social deprivation and TBI [26,27]. Children from low income families were less likely to receive clinical follow-up and adequate information on discharge from hospital. This may be because better off families are more able to pay for private help (e.g. rehabilitation, or counselling services), and these parents may be better equipped to seek out the information they need, and more able to discuss their requirements with medical staff.

Overall, 22% of the TBI group were described by their parents as 'accident prone' prior to the brain injury, significantly more than the 6.5% of the control group so described. This description gives an insight into pre-injury personality which may be characterised by risk-taking behaviour and a poor appreciation of safety and danger. It has been suggested that children who demonstrate behavioural problems following mild TBI may have also suffered these problems pre-morbidly [28]. However others have argued that this may not be the case [29]. Some of our respondents described their child as 'naughty' prior to the TBI, but that their behaviour had significantly worsened following the TBI.

Significant differences were observed in the frequency of problem reporting between children with TBI and control children. In particular there were significant differences between the moderate/severe TBI groups and controls for thirteen problem categories. Most notably family problems, behaviour, speech, temper, learning, and school problems. There were similar differences between the mild TBI and control groups, again most notably for behaviour, temper and school problems. However there were only four significant differences between the mild and moderate/severe groups.

Concentration, mood fluctuations and headaches were commonly reported by TBI groups. Furthermore, parents reported behavioural problems for approximately 40% of children in both mild and moderate/severe groups, and temper problems for approximately 60% of children in both groups.

Reports given by relatives of the brain injured person have been used successfully to assess outcome following TBI in adults (Brooks et al 1987) [30]. The study reported here largely relied on the reports of parents of children with TBI, and although subjective, the problems reported were genuinely important to respondents.

Parental reports of behavioural problems were confirmed by assessment on the VABS, whereby 90% of children described by their parents as having behavioural problems scored at the 'significant' maladaptive behaviour level, indicating clinically significant behavioural problems. There was also a strong association between the total number of problems reported and the VABS maladaptive behaviour score.

Also on the VABS, injured children demonstrated significantly higher levels of maladaptive behaviour than controls, yet there were no significant differences between the mild, moderate and severe TBI groups. At follow-up maladaptive behaviours amongst the TBI group showed no improvement, with 61.6% of injured children demonstrating 'significant' maladaptive behaviour compared to 5% of controls.

The incidence of behavioural problems reported for the mild group is higher than reported by most other studies. A possible explanation is that our mild group were at the more severe end of the spectrum of 'mild' TBI as all our subjects had been admitted to hospital for at least 24 hours. Furthermore, it is possible that the high frequency of problem reporting in the mild group may, in part, be due to the fact that parents volunteered to take part in this research following the postal survey, and may have wished to participate because of concerns about the behaviour of their child. To investigate this further the pattern of problem reporting in the interview group was compared to that of the postal questionnaire group, described elsewhere [31], to see whether the interview group were reporting more problems. We found that for both mild and moderate/severe groups, the interview group tended to report all problems slightly more frequently than the postal questionnaire group, a finding possibly due to the extra sensitivity of the face-to-face interview technique.

The problems which were reported spontaneously as of primary concern to parents were frequently headaches, behaviour, temper, mood, and physical problems. Anxiety was only a major concern for two families in the moderate/severe group. However, the HADS showed that in the moderate/severe group half of the children were either cases (9, 28%) or borderline cases (7, 21.9%) of clinically significant anxiety. Similarly, in the mild group 42.9% of children were either cases (5, 14.3%) or borderline cases (10, 28.6%). This indicates that parents did not consider their child's anxiety to be one of the problems worrying them most. Four children in the moderate/severe group attained HADS scores indicative of clinically significant depression, and there were 4 borderline cases in each of the mild and moderate/severe groups. This was partially reflected by the number of parents reporting 'mood' as a significant problem.

The age of the child at interview had little effect on the pattern of problem reporting. Younger children had more problems with temper, schoolwork and being bullied at school. There was no evidence to suggest that more recently injured children have more problems nor that their problems are more likely to resolve at twelve-month follow-up. Parents of children

with relatively recent mild injuries showed a tendency to report more problems, but this was not significant.

Many problems persist years post injury, even following mild TBI. At the twelve month follow-up very few problems (14.5% overall) had completed resolved. Those problems most likely to resolve were physical, whereas cognitive and intellectual problems tended to remain. For all TBI severity groups the majority of problems had stayed the same. In the control group twice as many problems had completely recovered at follow-up. These figures are similar to those found in the UK National Traumatic Brain Injury Study of 563 adults, which also showed that just over half of reported problems do not resolve over time [19]. The resolution of problems for children interviewed less than two years post injury was very similar to that of children interviewed more than two years post injury. It is likely that as the majority of our respondents were more than one year post injury at first interview, any short-term problems would have already resolved. Consequently, the problems being reported to us were of a more persistent nature.

Many of the parents welcomed the interviews as an opportunity to air their concerns and unanswered questions. All of the families who required support or someone to talk to were referred to the Brain Injury Liaison Nurse linked to the project, who discussed their concerns, and referred them on to a consultant paediatric neurologist where appropriate.

#### **Conclusions**

This study observed and examined the effects of a head injury on children, often several years post injury. Information and follow-up after TBI was inadequate in many cases, and structured rehabilitation rarely available. Children with mild, moderate and severe TBI reported similar problems, and most of these problems remained unresolved at follow-up. Many children demonstrated worrying levels of anxiety and maladaptive behaviour, and for most children these significant problems had gone unaddressed since the TBI. It is recommended that children hospitalised following a TBI should be routinely followed-up and assessed to identify problems which may affect their daily lives.

Further research is recommended to study a prospective group of head injured children in order to evaluate the effectiveness of additional interventions, such as improved information giving, routine follow-up and assessment, and to establish whether these interventions reduce the development of persistent problems.

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Table 1: Definitions of Injury Severity

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

Table 2: Participants in the three phases of the study according to injury severity

Injury Severity	Postal Questionnaire	First Interview	Second Interview
Mild	411	49	43
% of TBI group	78.3%	50.5%	50%
Moderate	61	19	17
% of TBI group	11.6%	19.6%	19.8%
Severe	49	29	26
% of TBI group	9.3%	29.9%	30.2%
Not recorded	4	0	0
% of TBI group	0.76	0%	0%
Total TBI Group	525	97	86
•	100%	100%	100%
Control Group	N/A	31	21
% of control group		100%	67.7%

Table 3 Demographics and Injury Characteristics

Variable	Mild n = 49	Moderate n = 19	Severe n= 29	All TBI n = 97	Control n = 31
Gender: number male (%)	32 (65.3%)	15 (78.9%)	17 (58.6%)	64 (66%)	18 (58.1%)
Age at injury (years)					NA
Mean	9.43	9.58	10.72	9.85	
SD	3.08	3.37	2.96	3.12	
Age at interview 1 (years)					
Mean	12.72	13.13	13.84	13.13	12.1
SD	3.43	3.95	3.42	3.53	3.16
Injury to interview 1 (years)					NA
Mean	2.33	2.68	1.97	2.29	
SD	1.52	1.60	1.50	1.53	
Ethnicity: number white (%)	48 (98%)	19 (100%)	29 (100%)	96 (99%)	31 (100%)
Ethnicity: number black (%)	1 (2%)	0	0	1 (1%)	0
Accident prone before injury (%)	12 (24.5%)	6 (31.6%)	3 (10.3%)	21 (21.6%)	NA
Accident prone controls (%)					2 (6.5%)
Mechanism of injury					N/A
Fall (%)	22 (44.9%)	4 (21.1%)	2 (7%)	28 (28.9%)	
RTA pedestrian (%)	9 (18.4%)	5 (26.3%)	17 (58.6%)	31 (32%)	
RTA in vehicle (%)	0	2 (10.5%)	4 (13.8%)	6 (6.2%)	
RTA cyclist (%)	4 (8.2%)	0	3 (10.3%)	7 (7.2%)	
Fall from bicycle (%)	8 (16.3%)	2 (10.5%)	0	10 (10.3%)	
Assault (%)	1 (2%)	2 (10.5%)	0	3 (3.1%)	
Object	4 (8.2%)	1 (5.3%)	1 (3.4%)	5 (5.2%)	
Other	1 (2%)	3 (15.8%)	2 (7%)	7 (7.2%)	
Total	49 (100%)	19 (100%)	29 (100%)	97 (100%)	

Table 4 Number of problems reported

Age Group	Mild n = 49	Moderate & Severe n = 48	Controls n = 31
Aged ≤10: no (%)	14 (28.6)	13 (27.1)	7 (22.6)
Mean no. problems	9.57	14.77	8.43
Median no. problems	10.0	15.0	10.0
SD	4.72	5.09	6.02
Range	1 - 18	6 - 23	1 - 18
	25 (51 1)	25 (52.0)	24 (55.4)
Aged $\geq 11$ : no (%)	35 (71.4)	35 (72.9)	24 (77.4)
Mean no. problems	8.97	13.06	4.75
Median no. problems	8.0	14.0	3.0
SD	6.16	7.11	4.11
Range	1 - 25	1 - 29	1 - 14
All Ages: no (%)	49 (100)	48 (100)	31 (100)
Mean no. problems	9.14	13.52	5.58
Median no. problems	9.0	14.0	4.0
SD	5.74	6.62	4.76
Range	1 - 25	1 - 29	1 - 18

Table 5: Most frequently reported problems at interview 1 by injury severity

Problem Item	Severe TBI No. reporting	Moderate TBI No. reporting	Mild TBI No. reporting	Controls No. reporting
	N = 29 (%)	N = 19 (%)	No. Teporting $N = 49 (\%)$	N = 31 (%)
Emotional Problems	22 (75.9)	15 (78.9)	36 (73.5)	20 (64.5)
(total reporting)	, ,	, ,	, ,	, ,
Aggression	6 (20.7%)	1 (5.3%)	3 (6.1%)	5 (16.1%)
Attitude to siblings#	10 (41.7%)	5 (29.4%)	15 (38.5%)	11 (37.9%)
Behaviour	11 (37.9%)	9 (47.4%)	19 (38.8%)	1 (3.2%)
Bullied	3 (10.3%)	2 (10.5%)	4 (8.2%)	0 (0%)
Mood fluctuations	18 (62.1%)	8 (42.1%)	30 (61.2%)	16 (51.6%)
Nightmares	4 (13.8%)	1 (5.3%)	2 (4.1%)	0 (0%)
Personality change	8 (27.6%)	3 (18.8%)	6 (12.2%)	5 (16.1%)
School behaviour	3 (14.3%)	5 (31.3%)	11 (24.4%)	3 (10.7%)
problems*				
Temper	17 (58.6%)	14 (73.4%)	29 (59.2%)	9 (29.0%)
Physical Problems	22 (75.9)	13 (68.4)	34 (69.4)	13 (41.9)
(total reporting)				
Clumsiness	4 (13.8%)	1 (5.3%)	3 (6.1%)	1 (3.2%)
Epilepsy	4 (13.8%)	2 (10.5%)	2 (4.1%)	0 (0%)
Headaches	18 (62.1%)	13 (68.4%)	32 (65.3%)	13 (41.9%)
Hearing	5 (17.2%)	4 (21.1%)	7 (15.6%)	1 (3.2%)
Mobility	5 (17.2%)	1 (5.3%)	4 (8.2%)	0 (0%)
Other physical problems	5 (17.2%)	1 (5.3%)	4 (8.2%)	0 (0%)
Sleep	10 (34.5%)	8 (42.1%)	9 (18.4%)	2 (6.5%)
Speech	11 (37.9%)	3 (18.8%)	6 (12.2%)	0 (0%)
Tiredness	12 (41.4%)	3 (15.8%)	15 (30.6%)	9 (29.0%)
Vision	10 (34.5%)	5 (26.3%)	12 (24.5%)	3 (9.7%)
Intellectual Problems (total reporting)	23 (79.3)	11 (57.9)	32 (65.3)	15 (48.4)
Concentration	21 (72.4%)	9 (47.4%)	29 (59.2%)	13 (41.9%)
Exam performance*	3 (14.3%)	2 (12.5%)	5 (11.1%)	0 (0%)
Learning*	14 (66.7%)	5 (31.3%)	12 (26.7%)	3 (10.7%)
Memory	15 (51.7%)	8 (42.1%)	20 (40.8%)	10 (32.3%)
Schoolwork*	8 (38.1%)	7 (43.8%)	18 (40.0%)	5 (17.9%)
Social Problems	25 (86.2)	13 (68.4)	21 (42.9)	5 (16.1)
(total reporting)	, ,	, ,	, ,	, ,
Family problems	12 (41.4%)	7 (36.8%)	6 (12.2%)	1 (3.2%)
Friendships	13 (44.8%)	7 (36.8%)	9 (18.4%)	4 (12.9%)
Lost Hobbies/ Activities	8 (27.6%)	1 (5.3%)	10 (20.4%)	N/A
School general problems*	11 (52.4%)	3 (18.8%)	12 (26.7%)	1 (3.6%)
Other Problems	16 (55.2)	6 (31.6)	13 (26.5)	N/A
(total reporting)				
Compensation	12 (41.4%)	0 (0%)	2 (4.1%)	N/A
Follow-up	5 (17.2%)	4 (21.1%)	10 (20.4%)	N/A
Information needs	4 (13.8%)	2 (10.5%)	4 (8.2%)	N/A
School unsympathetic*	5 (23.8%)	5 (31.3%)	7 (15.6%)	N/A

<sup>\*</sup> For problems associated with school percentages are calculated using only those children at school (15 children with TBI had left school). Numbers at school were: Severe: 21, Moderate: 16, Mild: 45, Controls: 28.

<sup>#</sup> For 'attitude towards siblings' percentages were calculated using only those children with siblings. Numbers with siblings were: Severe: 24, Moderate: 17, Mild: 39, Controls: 29.

Table 6: Controls versus Moderate and Severely Head Injured Children – Significant Differences in Problem Reporting

Problem Item	Pearson X <sup>2</sup>	Level of Significance
Family problems	13.17	p = 0.0001
Behaviour	12.11	p = 0.0001
Speech	10.05	p = 0.001
Sleep	9.60	p = 0.002
Temper	9.52	p = 0.002
Learning	8.38	p = 0.003
School problems	8.24	p = 0.004
Friendships	7.37	p = 0.006
Vision	6.86	p = 0.008
Mobility	4.19	p = 0.041
Physical	4.19	p = 0.041
Epilepsy	4.19	P = 0.041
Headaches	3.92	p = 0.049
Schoolwork	2.86	p = 0.093 (not sig.)

Table 7: Controls versus Mildly Head Injured Children – Significant Differences in Problem Reporting

<b>Problem Item</b>	Pearson X <sup>2</sup>	Level of Significance
Behaviour	11.77	p = 0.0001
School problems	6.31	p = 0.012
Temper	6.04	p = 0.014
Vision	4.28	p = 0.039
Headaches	4.21	p = 0.041
Speech	4.10	p = 0.043
Schoolwork	3.94	p = 0.048

Table 8: Mild versus Moderate and Severely Head Injured Children – Significant Differences in Problem Reporting

Problem Item	Pearson X <sup>2</sup>	Level of Significance
Family problems	9.47	p = 0.002
Compensation	8.59	p = 0.003
Friendships	6.28	p = 0.012
Sleep	4.42	p = 0.036
Speech	3.39	p = 0.067 (not sig.)

Most frequently reported problems at interview 1 by time since injury and Table 9 severity

Problem Category	Mild	Mild	Moderate/	Moderate/
	< 2 years post	≥ 2 years post	Severe	Severe
	injury $n = 15$	injury $n = 34$	< 2 years post	≥ 2 years post
	n (%)	n (%)	injury $n = 16$	injury $n = 32$
	(* *)	(,,,,	n (%)	n (%)
Aggression	1 (6.7)	2 (5.9)	2 (12.5)	5 (15.6)
Anxiety	2 (13.3)	0(0)	5 (31.3)	0 (0)
Attitude to siblings#	5 / 12 (41.7)	10 / 27 (37.0)	7 / 14 (50.0)	9 / 27 (33.3)
Behaviour	7 (46.7)	11 (32.4)	8 (50.0)	10 (31.3)
Bullied	2 (13.3)	2 (5.9)	2 (12.5)	3 (9.4)
Clumsiness	1 (6.7)	2 (5.9)	4 (25.0)	1 (3.1)
Compensation	1 (6.7)	1 (2.9)	5 (31.3)	7 (21.9)
Concentration	11 (73.3)	18 (52.9)	10 (62.5)	20 (62.5)
Epilepsy	0 (0)	2 (5.9)	2 (12.5)	2 (12.5)
Family problems	3 (20.0)	3 (8.8)	7 (43.8)	12 (37.5)
Follow-up	6 (40.0)	4 (11.8)	2 (12.5)	7 (21.9)
Friendships	5 (33.3)	4 (11.8)	6 (37.5)	14 (43.8)
Headaches	12 (80.0)	20 (58.8)	9 (56.3)	22 (68.8)
Hearing	3 (20.0)	4 (11.8)	2 (12.5)	7 (21.9)
Learning*	4 / 15 (26.7)	8 / 30 (26.7)	6 / 14 (42.9)	13 / 23 (56.5)
Lost hobbies/activities	5 (33.3)	5 (14.7)	5 (31.3)	4 (12.5)
Memory	8 (53.3)	12 (35.3)	7 (43.8)	16 (50.0)
Mobility	1 (6.7)	2 (5.9)	3 (18.8)	3 (9.4)
Mood fluctuations	11 (73.3)	19 (55.9)	11 (68.8)	15 (46.9)
Nightmares	1 (6.7)	0 (0)	3 (18.8)	0 (0)
Personality change	1 (6.7)	5 (14.7)	5 (31.3)	6 (18.8)
Physical problems	2 (13.3)	2 (5.9)	2 (12.5)	4 (12.5)
Schoolwork*	8 / 15 (53.3)	10 / 30 (33.3)	6 / 14 (42.9)	10 / 23 (43.5)
School behaviour	6 / 15 (40.0)	5 / 30 (16.7)	4 / 14 (28.6)	4 / 23 (17.4)
problems*				
School general problems*	5 / 15 (33.3)	7 / 30 (23.3)	5 / 14 (35.7)	9 / 23 (39.1)
School unsympathetic*	5 / 15 (33.3)	2 / 30 (6.7)	7 / 14 (50.0)	3 / 23 (13.0)
Sleep	4 (26.7)	5 (14.7)	8 (50.0)	10 (31.3)
Speech	2 (13.3)	4 (11.8)	5 (31.3)	8 (25.0)
Temper	11 (73.3)	17 (60.7)	12 (75.0)	19 (59.4)
Tiredness	4 (26.7)	11 (32.4)	4 (25.0)	10 (31.3)
Vision	5 (33.3)	7 (20.6)	5 (31.3)	10 (31.3)

<sup># =</sup> percentages calculated for children with siblings only
\* = percentages calculated for children at school at time of interview 1

Table 10 Problems most frequently reported spontaneously by parents and children

Problem Category	Mild Reported by parent N = 49 (%)	Moderate/ Severe Reported by parent N = 48 (%)	Mild Reported by child N = 49 (%)	Moderate/ Severe Reported by child N = 48 (%)
Emotional Problems		,		, ,
Anxiety	0 (0)	2 (4.2)	0(0)	0(0)
Behaviour	9 (18.4)	10 (20.8)	2 (4.1)	2 (4.2)
School behaviour	2 (4.1)	2 (4.2)	0(0)	0 (0)
Mood fluctuations	5 (10.2)	9 (18.8)	1 (2.0)	1 (2.1)
Personality change	2 (4.1)	7 (14.6)	0(0)	1 (2.1)
Temper	8 (16.3)	7 (14.6)	2 (4.1)	2 (4.2)
Other Emotional	4 (8.2)	7 (14.6)	0(0)	1 (2.1)
No. reporting				
Emotional problems	19 (38.8)	23 (47.9)	3 (6.1)	6 (12.5)
Physical Problems				
Headaches	13 (26.5)	11 (22.9)	16 (32.7)	7 (14.6)
Speech	1 (2.0)	6 (12.5)	1 (2.0)	0(0)
Vision	4 (8.2)	1 (2.1)	3 (6.1)	2 (4.2)
Other physical	17 (34.7)	18 (37.5)	4 (8.2)	7 (14.6)
No. reporting Physical				
problems	26 (53.1)	22 (45.8)	21 (42.9)	16 (33.3)
Intellectual Problems				
Concentration	8 (16.3)	6 (12.5)	1 (2.0)	0(0)
Memory	1 (2.0)	5 (10.4)	2 (4.1)	3 (6.3)
Schoolwork*	5 (10.2)	7 (14.6)	1 (2.0)	4 (8.3)
Learning	2 (4.1)	2 (4.2)	0 (0)	1 (2.1)
No. reporting				
Intellectual problems	8 (16.3)	17 (35.4)	3 (6.1)	7 (14.6)
None	10 (20.4)	7 (14.6)	24 (49%)	26 (54.2)

Table 11 Vineland Maladaptive Behaviour Categories for first and second interviews

Vineland Maladaptive Behaviour	Mild N (%)	Moderate N (%)	Severe N (%)	Control N (%)
2014 (1041				
<i>Interview 1 :</i> n=	35	15	23	10
Not significant	9 (25.7%)	2 (13.3%)	3 (13%)	7 (70%)
Intermediate	4 (11.4%)	3 (20%)	4 (17.4%)	0 (0%)
Significant	22 (62.9%)	10 (66.7%)	16 (69.6%)	3 (30%)
Interview 2: n=	44	16	26	20
Not significant	11 (25%)	4 (25%)	4 (15.4%)	10 (50%)
Intermediate	8 (18.2%)	3 (18.8%)	3 (11.5%)	9 (45%)
Significant	25 (56.8%)	16 (56.3%)	19 (73.1%)	1 (5%)

Table 12 Hospital Anxiety and Depression Scale (HADS) Categories: Interviews 1 and 2

<b>HADS Category</b>	Mild	Moderate/ Severe	Control
Interview 1: n=	35	32	14
Anxiety			
Cases (%)	5 (14.3%)	9 (28.1%)	1 (7.1%)
Borderline (%)	10 (28.6%)	7 (21.9%)	0 (0)
Non-cases (%)	20 (57.1%)	16 (50%)	13 (92.9%)
Depression			
Cases (%)	0 (0%)	4 (12.5%)	0 (0)
Borderline (%)	4 (11.4%)	4 (12.5%)	1 (7.1%)
Non-cases (%)	31 (88.6%)	24 (75%)	13 (92.9%)
Interview 2: n= Anxiety	26	26	11
Cases (%)	3 (11.5%)	7 (26.9%)	3 (27.3%)
Borderline (%)	7 (26.9%)	5 (19.2%)	0 (0)
Non-cases (%)	16 (61.5%)	14 (53.8%)	8 (72.7%)
Depression			
Cases (%)	0 (0%)	2 (7.7%)	0 (0)
Borderline (%)	3 (11.5%)	2 (7.7%)	0 (0%)
Non-cases (%)	23 (88.5%)	22 (84.6%)	11 (100%)

Table 13 Problem resolution at follow-up

Problem Resolution Scale	Mild N = 43 N (%)	Moderate N = 17 N (%)	Severe N = 26 N (%)	Control N = 21 N (%)
Number of problems revisited	351	168	405	105
Completely Recovered	70 (19.9)	20 (11.9)	44 (10.9)	30 (34.9)
Almost completely recovered	48 (13.7)	12 (7.1)	30 (7.4)	7 (6.6)
Improved but still significant	50 (14.2)	14 (8.3)	63 (15.6)	10 (9.4)
Stayed the same	153 (43.6)	109 (64.5)	236 (58.3)	48 (45.3)
Got worse	30 (8.5)	13 (7.7)	32 (7.9)	4 (3.8)

Table 14 Problems which resolve at follow-up

Problem Item	Mild Problem	Moderate/ Severe	Mild Problem same	Moderate/ Severe
	completely	Problem	or worse	Problem same
	resolved	completely	N / number reporting int.1	or worse
	N / number reporting int.1	resolved N / number	(%)*	N / number reporting int.1
	(%)*	N / number reporting int.1 (%)*		(%)*
Aggression	0/3(0)	0/7(0)	1 / 3 (33.3)	4 / 7 (57.1)
Attitude to siblings	0 / 15 (0)	0 / 15 (0)	8 / 15 (53.3)	11 / 15 (73.3)
Behaviour	2 / 19 (10.5)	1 / 20 (5.0)	9 / 19 (47.4)	12 / 20 (60.0)
Bullied	2 / 4 (50.0)	1 / 5 (20.0)	0 / 4 (0)	3 / 5 (60.0)
Clumsiness	2 / 3 (66.7)	0 / 5 (0)	1 / 3 (33.3)	4 / 5 (80.0)
Compensation	0 / 2 (0)	1 / 12 (8.3)	2 / 2 (100)	9 / 12 (75.0)
Concentration	4 / 29 (13.8)	1 / 30 (3.3)	13 / 29 (44.8)	22 / 30 (73.3)
Epilepsy	0 / 2 (0)	2 / 6 (33.3)	0 / 2 (0)	2 / 6 (33.3)
Exam performance	0 / 5 (0)	0 / 5 (0)	2 / 5 (40.0)	2 / 5 (40.0)
Family problems	2 / 6 (33.3)	5 / 29 (17.2)	1 / 6 (16.7)	11 / 29 (37.9)
Follow-up	2 / 10 (20.0)	0/9(0)	5 / 10 (50.0)	6 / 9 (66.7)
Friendships	1/9(11.1)	2 / 20 (10.0)	0/9(0)	11 / 20 (55.0)
Headaches	5 / 32 (15.6)	5 / 31 (16.1)	10 / 32 (31.3)	9 / 31 (29.0)
Hearing	4 / 7 (57.1)	2/9(22.2)	2 / 7 (28.6)	6 / 9 (66.7)
Information needs	0 / 4 (0)	0 / 6 (0)	2 / 4 (50.0)	4 / 6 (66.7)
Learning	0 / 12 (0)	2 / 19 (10.5)	4 / 12 (33.3)	12 / 19 (63.2)
Lost hobbies/activities	0 / 10 (0)	2 / 9 (22.2)	5 / 10 (50.0)	7 / 9 (77.8)
Memory	5 / 20 (25.0)	1 / 23 (4.3)	8 / 20 (40.0)	15 / 23 (65.2)
Mobility	2 / 4 (50.0)	1 / 6 (16.7)	1 / 4 (25.0)	4 / 6 (66.7)
Mood fluctuations	3 / 30 (10.0)	0/26(0)	16 / 30 (53.3)	19 / 26 (73.1)
Nightmares	0/2(0)	0/5(0)	1 / 2 (50.0)	1 /5 (20.0)
Personality change	1/6 (16.7)	0 / 11 (0)	4 / 6 (66.7)	6 / 11 (54.5)
Physical problems	2 / 4 (50.0)	0/6(0)	0/4(0)	5 / 6 (83.3)
Schoolwork	1 / 18 (5.6)	1 / 15 (6.7)	6 / 18 (33.3)	10 / 15 (66.7)
School behaviour	3 / 11 (27.3)	1/8(12.5)	3 / 11 (27.3)	6 / 8 (75.0)
problems	` ,	,	,	` '
School general	1 / 12 (8.3)	0 / 14 (0)	4 / 12 (33.3)	11 / 14 (78.6)
problems	` ,	. ,	,	, ,
School unsympathetic	1 / 7 (14.3)	0 / 10 (0)	3 / 7 (42.9)	8 / 10 (80.0)
Sleep	2 / 9 (22.2)	6 / 18 (33.3)	1/9(11.1)	6 / 18 (33.3)
Speech	3 / 6 (50.0)	3 / 14 (21.4)	2 / 6 (33.3)	8 / 14 (57.1)
Temper	2 / 29 (6.9)	0/31(0)	15 / 29 (51.7)	21 / 31 (67.7)
Tiredness	3 / 15 (20.0)	0 / 15 (0)	5 / 15 (33.3)	8 / 15 (53.3)
Vision	5 / 12 (41.7)	4 / 15 (26.7)	4 / 12 (33.3)	6 / 15 (40.0)

 $<sup>\</sup>ast$  percentage of those reporting each problem at interview 1

# Appendix I

# 1. Any problems with (describe):

- a) Sight?
- b) Hearing?
- c) Memory?
- d) Concentration/attention?
- e) Does child find learning more difficult than before?
- f) Fits?
- g) Speech?
- h) Headaches?
- i) Sleeping?
- j) Tiredness?
- k) Changes in mood?
- 1) Changes in temper?
- m) Problems with behaviour at home?
- n) Attitudes towards brothers and sisters?
- o) Problems with behaviour at school?
- p) Increased/decreased smoking/drinking?

# **2. Physical independence** Describe degree of independence in self-care and dependence on aids

- i) Reliance on others?
- ii) Reliance on aids?
- iii) Reduction in scope of activities?

## **3. Mobility** Describe ability to move about effectively

- i) How reliant is client on others for mobility?
- ii) How does client manage community mobility and transport?

# 4. Occupation

- i) Describe daily activities typical day
- ii) Is this any different from before?

# **5. Social Integration** Level of contact with a widening circle and relationships with others

- i) Friendships
- ii) Different from before?

## 6. Financial Burden

- i) Has the head injury affected the family finances in any way?
- ii) If so how?

# 7. What changes has child made since the accident:

- i) Accommodation
- ii) Education (e.g. change of class, subjects studied, change of school)
- iii) Employment (if any)
- iv) Leisure/hobbies