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Title: PARENTAL STRESS AND BURDEN FOLLOWING TRAUMATIC BRAIN INJURY AMONGST CHILDREN AND ADOLESCENTS

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Abstract

Primary objectives: to assess parental stress following paediatric traumatic brain injury (TBI) and examine the relationship between self-reported problems and parental stress and general health.

Research design: controlled interview study

Methods and procedures: Parents of ninety-seven children admitted with a TBI (49 mild, 19 moderate, 29 severe) were identified from a case register of all paediatric admissions from 1992-1998. Parents of 31 uninjured children acted as controls. Structured interviews were carried out with families, and parents assessed on the Parenting Stress Index (PSI/SF) and General Health Questionnaire (GHQ-12) at recruitment, and repeated 12 months later.

Main outcomes and results: regardless of injury severity, parents of injured children suffered greater stress than control parents as measured by the PSI/SF (p = 0.001). There was a highly significant relationship between number of problems reported and level of parental stress (p = 0.001). Financial burden was related to severity of TBI.

Conclusions: improved information, follow-up, and support is likely to reduce parental stress and family burden.

Introduction

It has long been recognised that traumatic brain injury (TBI) affects not just the injured individual, but the whole family [1-3]. A person with a serious TBI can unwittingly place an emotional and financial burden on his or her family. Those most vulnerable to this burden are the people sharing a home with the injured person, for adults this is often the spouse, but for children and adolescents it is usually their parents.

Those caring for and living with an adult who has experienced TBI report significant levels of burden and distress [4, 5]. Clinically significant levels of anxiety, depression, and impaired social adjustment have been observed at six months post-injury for over one third of those caring for people with severe TBI [6]. Importantly, emotional and social distress amongst caregivers and relatives does not diminish over time, and can often increase [7, 8]. In particular, primary caregivers, usually mothers or wives, experience greater psychological distress and worse psychosocial outcome than other caregivers [9]. Furthermore, a TBI is likely to place a significant financial burden on the family of the injured person [10] which in can, in turn, negatively affect their quality of life.

When a child has a traumatic brain injury resulting in hospital admission, parents are placed under considerable strain. Initially they are likely to worry about their child’s survival, and subsequently they may feel guilty that the child was injured in the first place. When the child returns home after hospital discharge, parents assume the role of caregivers which may cause them to adjust their own lives, particularly in terms of employment and social activities. Following a serious TBI a child is at risk of ongoing neuropsychological, behavioural and intellectual problems [11–13]. These problems are likely to place additional strain upon his or her parents. Rivara et al [14-16] followed the families of children with TBI for three years post-injury. They observed that family functioning deteriorated over time for the families of children with severe TBI. More recently Wade et al [17] assessed parents of children with severe and moderate TBI up to one year post-injury, comparing them with a control group of parents with a child who had suffered orthopaedic injuries. They reported significantly higher levels of family burden, injury related stress, and psychological symptoms amongst parents in the TBI groups than amongst parents in the orthopaedic group.

It has been argued that parental stress may impair the parents' ability to adjust to the new and possibly substantial demands of the brain injured child, which may in turn prevent them from being able to provide the calm and structured environment a child will need following a brain injury [18]. Consequently there is a need for research which can identify the causes of parental stress and can recommend ways in which this stress may be reduced.

The study described here was carried out to examine the relationship between the brain-injured child's perceived problems and parental stress and parental general health, and to compare the problems and stress suffered by families of a child with TBI, with the problems and stress suffered by families of non-injured control children. Assessments were carried out at recruitment to the study and repeated twelve months later. The financial burden placed upon the family following the child's TBI was also assessed, as were the parents' information requirements. The study had the following primary objectives:

1 To compare levels of stress amongst parents of children with a mild, moderate and severe TBI, and with stress exhibited by parents of non-injured control children.

2 To compare the general and psychological health of parents in the TBI and control groups.

3 To examine the relationship between reported problems and parental stress and general health

4 To examine the financial burden a TBI places upon families.

5 To examine information and follow-up requirements

6 To identify potential causes of parental stress and recommend ways in which this may be reduced and services improved for parents of a child with TBI.

Methods

Study Population

North Staffordshire Hospitals National Health Service Trust has maintained a brain injury register of all children admitted for ≥24 hours with a TBI since November 1992 to the present. Details of the cause of injury, injury severity, and length of hospital stay are recorded by a dedicated brain injury nurse. In 1998 and 1999 a postal questionnaire was sent to parents of all 974 surviving children on the register who were aged 5-15 years at the time of the injury. Five hundred and twenty-five parents completed and returned the questionnaire. At the end of the questionnaire parents were invited to take part in an interview and assessment study, and over one quarter of parents (139, 26.5%) volunteered to take part. The severity of each child's brain injury was determined using Glasgow Coma Scale (GCS) [19] scores where recorded and/or the duration of unconsciousness following the TBI. Using the

British Society of Rehabilitation Medicine classification of severity [20] (shown in Table 1) 90 of these children had mild TBI, 19 moderate TBI, 29 severe TBI, and for 12 children injury severity was unspecified. 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.

Ninety-seven young people with TBI and their parents formed the interview study group. Of these, 29 (29.9%) children had severe brain injuries, 19 (19.6%) moderate, and 49 (50.5%) mild. Interviews were carried out with the whole family wherever possible, including mother, father, the injured child and siblings. However, the person with most responsibility for the injured child was typically the mother (99% of families).

Table 1 about here

Control group

At the interview with the family of the brain injured child, the family was asked to suggest a family with a child of the same age, sex, 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, 31 of these agreed to participate in the study. This formed a control group with approximately the same age profile as the TBI groups (shown in table 2). An Analysis of Variance (ANOVA) of ‘severity’ X ‘age at interview 1’ showed no difference between the TBI and control groups (F = 0.71, df = 3, p = 0.55).

Table 2 about here

Measures

Information on the child's problems and difficulties was collected using a structured questionnaire developed for the study. Parents were first invited to report problems spontaneously, then were prompted using a list of possible problem categories. These categories were: emotion, behaviour, physical, intellectual, school issues, social integration, leisure activities, employment, and family problems. Parents were also questioned about the effect of the TBI on their own income, expenditure, employment, and leisure activities.

The Parenting Stress Index Short Form (PSI/SF) [21] was used to measure the level of stress suffered by the primary carer, usually the mother, at the time of the interviews. This instrument measures stress over four domains: parental distress (PD); parent-child dysfunctional interaction (P-CDI); difficult child (DC); and total stress (TC). For each domain, raw scores are converted into percentile scores derived from the frequency distribution of the normative sample [21]. The normal range for scores is within the 15th to 80th percentiles. A score at or above the 85th percentile is considered high, and scores at or above the 90th percentile indicate a clinically significant abnormal score which may require professional assistance. A high score on the Difficult Child domain indicates that the child demonstrates difficult, defiant and demanding behaviour. A high score on the P-CDI domain suggests that the parent-child bond is threatened or has never been adequately established.

The General Health Questionnaire short version GHQ-12 [22] was used to measure the general health of the primary carer at the time of the interviews, again usually the mother. This is a self-administered screening test, with a focus on psychological components of illhealth, aimed at detecting psychiatric disorders amongst respondents in community settings or amongst general medical outpatients [22]. The instrument assesses symptoms such as concentration, confidence, anxiety and depression. The twelve symptoms have four possible responses, typically: ‘not at all’; ‘no more than usual’; ‘more than usual’; and ‘much more than usual’. Responses were scored using the simple Likert scoring method (0-1-2-3) potentially giving a minimum score of 0 and a maximum score of 36.

The Problem Resolution Scale, developed for a UK study of adults with TBI [23] was used at follow-up. This instrument monitors changes in reported problems over time using a five point scale whereby: 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. Prior to the interview, informed written consent was obtained from the parent, and for children over the age of 13 from the child him/herself. Ninety-seven parents and children were interviewed face-to-face in their own homes by two highly experienced interviewers.

The interview was structured. Initially, parents and children were asked if there were any problems or difficulties following the head injury that were of particular concern to them. Then, respondents were prompted using a check-list of problems. Parents were also asked about the services they had received from health, social, and education agencies.

The control children and parents were interviewed and assessed in their own homes by trained Psychology Assistants.

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 April 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 GHQ-12 and the PSI/SF were readministered.

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

Statistical analyses

Descriptive statistics including means and standard deviations were calculated for demographic 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. All children recruited to the study were aged between 5 and 15 years at the time of the brain injury. The mean age at the time of injury was 9.85, SD = 3.12. However, some of the injuries took place up to 5 years before the start of the study. At first interview participants ranged from age 6 to 20, with a mean age of 13.13 years, SD = 3.53. All of the children were following a normal course of education at the time of the TBI. By the time of first interview fifteen participants had completed their schooling. Table 2 shows demographic and injury characteristics of children in each severity group and in the control group.

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 2.

Parent characteristics

The marital, employment, and economic status of parents in each of the TBI groups and the control group at the time of the initial interview is shown in table 3. At the time of the interviews, 22 respondents (22.7%) were single parents, 62 (63.9%) were married, and 13 (13.4%) were living with a partner. Most (99%) primary carers were mothers, and approximately one quarter of the TBI group (22.7%) were home-makers without any paid employment, compared to only 13% of the control group. One quarter of the TBI group were unskilled workers (25.8%) compared to one third of the control group (35.5%).

Economic self-sufficiency was estimated using scale categories identified in the World Health Organisation International Classification of Impairments, Disabilities and Handicaps (ICIDH)

[24]. A higher proportion of families in the control group were comfortably off (9, 29%), compared to the TBI group (11, 11.3%). However just over half of the TBI group were fully self-sufficient (50, 51.5%).

Table 3 about here.

Social deprivation and ethnicity

Social deprivation was measured using Townsend Deprivation Scores [25] which were calculated using postcodes. Valid postcodes were available for 94 families in the TBI group, and 27 families in the control group. The higher the positive score the more deprived an area, and the higher the negative score the more prosperous. In both the TBI and control groups two thirds (67% TBI, 63% control) of families lived in areas with positive scores. For the TBI group the mean score was +1.24, SD = 2.84, with a range of –5.14 to +8.29. For the control group the mean score was –0.16, SD = 2.69, with a range of –4.93 to +5.1.

The population of North Staffordshire is predominantly white [26]. This was reflected by our respondents, 99% of whom were white.

Interval between injury and first interview

Parents were interviewed between 6 months and 5 years following their child’s TBI. The mean interval between injury and interview was 2.29 years, SD = 3.53. Fifteen children (11.7%) were less than 1 year post-injury at the time of first interview.

Other injuries

Fifty-four children had suffered other injuries at the time of the brain injury, representing 55.7% of the TBI group. These were either serious such as fractures to arms, legs, or pelvis; broken legs or wrists; chest injuries; or facial injuries (30 children, 30.9%), or minor injuries such as cuts, grazes, and bruises (24 children, 24.7%). At first interview these other injuries were still giving problems for 31 (32%) of the TBI group, remaining a problem for 17 (34.7%) in the mild group, 5 (26.3%) in the moderate group, and 9 (31%) in the severe group.

Information and follow-up received at hospital discharge

Of the 49 families of a child with a mild TBI, 17 (34.7%) said that they had received no information from the hospital following their child's admission. Thirty-two (65.3%) had received some information, usually a leaflet of symptoms to look out for during the first few days following hospital discharge. Of these, fourteen respondents (43.8%) did not find the information very helpful, and were left unsure of any long-term consequences of the injury. A follow-up appointment was offered to only 19 (38.8%) children with mild TBI.

Of the 19 families of a child with a moderate TBI, 8 (42%) said that they had not received any information from the hospital following their child's admission. Of the 11 (57.9%) who did receive information, only 4 (36.4%) found the information helpful. Only 11 (57.9%) children with moderate TBI received a follow-up appointment after discharge.

Of the 29 families of a child with a severe TBI, 10 (34.5%) said that they had not received any information from the hospital following their child's admission. Of the 19 who had received information, only 9 (47.4%) found it helpful. Of the 29 children with severe TBI, 23 (79.3%) were seen at a follow-up appointment after discharge.

Therapeutic input

Following the TBI, four children in the severe group had received multi-disciplinary rehabilitation, seven children in the severe group had received physiotherapy, two children (one severe, one moderate TBI) had received psychological input, and one child (moderate TBI) had received psychiatric input. At the time of the first interview three children, all with severe TBI, were continuing to receive therapy.

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). The severe TBI group reported most problems, with a mean of 15.2 problems per family (SD=6.31). The moderate TBI group reported a mean of 10.9 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 in the frequency of problem reporting between the mild, moderate, severe, and control groups (F = 14.51, df = 3, p = 0.0001). A significant difference was also observed between the mild, moderate, and severe TBI groups (F = 9.21, df = 2, p = 0.0001).

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 4. Problems were divided into emotional, physical, intellectual, family, and ‘other’ problems concerning insurance claims, follow-up and information needs. For each problem category the means were compared using an ANOVA of the ‘Group’ x ‘number of problems’. For emotional problems there were no significant differences between the three TBI groups, between the TBI groups and controls, nor between the severe TBI and control groups. This was largely due to the high proportion of control children with problems of mood. Taking behavioural problems separately, there were no significant differences between the TBI groups, but there were differences between the TBI groups and the control group (F = 4.86, df = 3, p = 0.003), and particularly between the severe TBI and control groups (F = 11.29, df = 1, p = 0.001).

For physical problems there were no significant differences between the TBI groups, but there were differences between the TBI groups and the control group (F = 3.17, df = 3, p = 0.027), and between the severe TBI and control groups (F = 7.78, df = 1, p = 0.007). For intellectual problems there were no significant differences between the TBI groups, nor between the TBI groups and controls, there was a significant difference between the severe TBI and control groups (F = 6.648, df = 1, p = 0.012). For family problems there were significant differences between the mild, moderate, and severe groups (F = 5.16, df = 2, p = 0.007), between the TBI and the control groups (F = 7.08, df = 3, p = 0.0001), and between the severe TBI and control groups (F = 15.81, df = 1, p = 0.0001). For ‘other’ problems there were no differences between the TBI groups for problems with follow-up and information needs, but there was a significant difference between the TBI groups for problems with an insurance claim (F = 15.89, df = 2, p = 0.0001).

Table 4 about here.

Parental health at first interview

The GHQ-12 was used to assess the psychological health of the primary carer. Assessments were carried out with 93 parents in the TBI groups: 47 in the mild group, 18 in the moderate group, and 28 in the severe group. In the control group 18 primary carers were assessed.

Responses were scored using the simple Likert scoring method (0-1-2-3) potentially giving a minimum score of 0 and a maximum score of 36. Table 5 shows the means, range and SD for each severity group and the control group. A score of 18 or above represents a high proportion of reporting at the ‘rather more than usual’ and ‘much more than usual’ level. Consequently a threshold score of ≥18 was used to compare the groups. No parents of control children had a score above 14, and 15-18% of each of the three TBI severity groups scored ≥18.

Comparison of means using an ANOVA of the ‘Group’ x ‘total GHQ score at Interview 1’ found a statistically significant difference between the mild, moderate, severe and control groups (F = 4.59, df = 3, p = 0.005). However, no significant difference was observed between the mild, moderate and severe TBI groups (F = 1.47, df = 2, p = 0.24).

Table 5 about here.

Parental stress at first interview

The Parenting Stress Index Short Form (PSI/SF) was used to measure stress amongst parents of injured and control children. The mean percentage scores and standard deviations for Total

Stress and three sub-scales of the PSI/SF are shown in table 6 for each severity group and the control group. Parents of severely injured children scored consistently higher than parents of children with mild or moderate TBI on all dimensions, but not significantly so. For Total Stress parents in the severe group had a mean score of 78.1%, and in the mild group the mean score was 65.3%. Means were compared using an ANOVA of the 'Group' x 'percentage score', for Total Stress and each of the three sub-scales. There were no significant differences between the mild, moderate, and severe TBI groups for Total Stress (TS), Parent-Child Dysfunctional Interaction (P-CDI), or Difficult Child (DC). There was a significant difference between the TBI groups on the Parental Distress (PD) sub-scale ($F = 4.02$, $df = 2$, $p = 0.021$).

Highly significant differences were observed on all four dimensions between the mild, moderate, severe, and control groups: TS: $F = 6.83$, $df = 3$, $p = 0.0001$; P-CDI: $F = 3.53$, $df = 3$, $p = 0.017$; DC: $F = 6.96$, $df = 3$, $p = 0.0001$; and PD: $F = 5.97$, $df = 3$, $p = 0.001$.

Table 6 about here.

Table 6 also shows the number and percentage of parents scoring at or above the clinically significant 90th percentile for each sub-scale. A higher percentage of parents in the severe TBI group demonstrated clinically significant stress than in the mild and moderate TBI groups. The Pearson Chi-squared test was used to measure differences between the three severity groups and controls for the number of parents scoring ≥ 90th percentile on each of the PSI/SF dimensions. There was a significant difference between the groups for Total Stress ($X^2 = 20.25$, $df = 3$, $p = 0.0001$), and for all three sub-scales: P-CDI: $X^2 = 7.79$, $df = 3$, $p = 0.051$; DC: $X^2 = 23.37$, $df = 3$, $p = 0.0001$; and PD: $X^2 = 10.78$, $df = 3$, $p = 0.013$.

A significant number of parents in the severe group scored at the 99th percentile on PSI/SF dimensions: 9 parents (31%) scored 99% for total stress, 9 (31%) for parent-child dysfunctional interaction, 5 (17.2%) for difficult child, and 1 (3.4%) for parental distress. In the moderate group 3 parents (15.8%) scored 99% for total stress, 4 (21.1%) on DC, 3 (15.8%) on P-CDI, and 1 (5.3%) on PD. In the mild group 5 (10.4%) scored 99% for total stress, 11 (22.9%) on P-CDI, and 5 (10.4%) on DC.

The relationship between reported problems and parental stress and parental health

In order to analyse the relationship between perceived problems and parental stress, all families (TBI and control) were grouped into one of three problem bands, according to the number of problems they reported at interview. These bands were high (13 – 29 problems reported), medium (7 – 12) and low (1 – 6). On the PSI/SF, for total stress and each of the three sub-scales, parents were placed in one of two groups 1) those scoring within the abnormal range of ≥ 85%, and 2) those with scores <85%. Crosstabulations were then carried out on 'problem band' x 'PSI/SF domain'. For total stress, 72.7% of parents with more than 12 problems had abnormal PSI/SF scores at or above 85th percentile. On the difficult child domain, 82% of parents reporting a high number of problems scored at or above 85th percentile. Highly significant relationships were found between total stress, P-CDI, and DC and the number of problems reported at first interview ($p = 0.0001$), and a significant relationship was found between PD and the number of problems reported ($p = 0.004$).

The relationship between perceived problems and parental health was analysed in the same way. Parents were placed in one of two groups according to their total score on the GHQ-12: 1) high scores of ≥ 18, and 2) low scores of < 18. Crosstabulations were then carried out on ‘problem band’ x ‘GHQ-12 group’. A significant relationship was observed between parental health and number of problems reported. Results are shown in table 7. This table shows the number of parents in each problem band scoring at or above the 85th percentile on each PSI/SF domain, and those scoring ≥ 18 on the GHQ-12.

Table 7 about here.

Financial burden on families following the TBI

For 56 families (57.7%), at least one parent had taken time off work because of their child’s TBI. In the severe group this figure was 79.3%, representing 23 families. Furthermore, 43 (44.3%) of these families lost income because of the TBI. Most parents were working at the time of the TBI, and the majority did not receive paid leave from their employers after the injury when they took time off to accompany the child in hospital, or to care for the child after hospital discharge. Approximately 70% of the parents of mild and moderately injured children took unpaid leave, and 61% of the parents of severely injured children took unpaid leave. The TBI caused lost income for 69% of families in the severe group, and 20.6% and 42% in the mild and moderate groups respectively. The sum lost ranged from £120 to £10,000. In 31% of families with a severely injured child at least one working parent gave up their job to care for the child, usually the mother. Despite these considerable effects on family finances, only four families in the severe group and one in the mild group reported that they had received some financial support from Social Services. Table 8 gives details of the financial burden on families as a result of the TBI.

Table 8 about here.

Following the TBI, many parents reported that additional expenditure was required to purchase additional items, for example aids for the child and adaptations to their home. This was necessary for two thirds of families in the severe group, half the families in the moderate group, and one quarter of families in the mild group. Three families in the severe group and three families in the mild group moved home because of the TBI. In the severe group this was due to the need for significantly adapted accommodation. In the mild group this was because the TBI had occurred in a road accident close to their former home, and parents wished to remove their child away from the source of danger. Additional transport costs were a further burden on the family budget. These included costs of travel for the parents to visit the child in hospital, to transport the child to therapy and assessment sessions, and to transport the child to and from school as he or she was no longer able to travel independently.

Reduced leisure activities

Many parents reported reduced leisure activities for themselves and the family as a whole. In the severe group, 23 (79.3%) parents had ceased or reduced their leisure activities following the TBI, as did 14 (73.7%) in the moderate group, and 25 (51.0%) in the mild group.

Follow-up interviews and assessments

In the TBI group 86 families were followed-up, interviewed, and re-assessed using the same measures twelve months after the first interviews. Only two children had received some therapeutic input from health professionals during the interval between first and second interviews.

Problem resolution at follow-up

At the second interview each of the previously reported problems were discussed and, using the categories defined in the Problem Resolution Scale (PRS), 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.

In the control group twenty-one families were followed-up. One hundred and five problems were revisited using the PRS scoring system, 30 (34.9%) problems had completely recovered, 7 (6.6%) problems had almost completely recovered, 10 (9.4%) had improved but were still significant, 48 (45.3%) of problems remained the same, and 4 (3.8%) had worsened.

Parental health at follow-up

Follow-up GHQ-12 assessments were carried out with 81 parents in the TBI group, 42 in the mild group, 16 in the moderate group, and 23 in the severe group. In the control group 20 parents were assessed. Table 5 shows the means, range, and SD for each severity group and the control group at second interview. Scores of ≥18 were obtained by a higher proportion of parents in the severe group than at first interview, 34.8% compared to 17.9% previously. In the other groups the number of parents scoring ≥18 were one in the moderate group, six in the mild group, and none in the control group.

Comparison of means using an ANOVA of the ‘Group’ x ‘total GHQ-12 score at Interview 2’ found statistically significant differences between the mild, moderate, severe, and control groups (F = 4.32, df = 3, p = 0.007), and between the mild, moderate, and severe groups (F = 3.07, df = 2, p = 0.05).

Parental stress at follow-up

The PSI/SF was re-administered at follow-up. The mean percentage scores and standard deviations for Total Stress and three sub-scales of the PSI/SF for each severity group and the control group are shown in table 6. Parents of severely injured children continued to score consistently higher than parents of children with mild or moderate TBI on all dimensions. Scores for Total Stress remained almost unchanged from the first interview. Parents in the severe group had a mean score of 78.3%, and in the mild group the mean score was 62.2%. Means were compared using an ANOVA of the ‘Group’ x ‘percentage score’, for Total Stress and each of the three sub-scales. There were no significant differences between the mild, moderate, and severe groups for Total Stress (TS), Parent-Child Dysfunctional Interaction (P-CDI), or Difficult Child (DC). There was a significant difference on the Parental Distress (PD) sub-scale (F = 3.37, df = 2, p = 0.04). Significant differences were observed between the mild, moderate, severe, and control groups on three dimensions: TS: F = 3.93, df = 3, p = 0.01; DC: F = 4.25, df = 3, p = 0.007; PD: F = 3.49, df = 3, p = 0.02; but failed to reach significance on the P-CDI : F = 2.47, df = 3, p = 0.066.

The Pearson Chi-squared test was used to measure differences between the three severity groups and controls for the number of parents scoring ≥ 90th percentile on each of the PSI/SF dimensions at follow-up. There was a significant difference between the groups for Total

Stress (X^2 = 9.21, df = 3, p = 0.027), and for two sub-scales: P-CDI: X^2 = 12.68, df = 3, p = 0.005; DC: X^2 = 7.76, df = 3, p = 0.051; but not for PD: X^2 = 2.16, df = 3, p = 0.54.

Discussion

This study has found that parents of children who have suffered a traumatic brain injury suffer significantly greater stress than parents of healthy control children. This was true for parents of mild, moderate, and severe TBI as no significant differences were found between the severity groups for total stress, parent-child dysfunctional interaction, or 'difficult child' on the PSI/SF. There were no significant differences between the severity groups for parental general health, parents of children with a mild TBI scored almost as highly as parents of children with a severe TBI. However, there were significant differences between parents of the TBI group and parents of control children. The study found that the number of problems reported by parents is related to injury severity, the greater the injury severity, the greater the number of problems. There was a highly significant relationship between the number of problems reported by parents and levels of parental stress, with 73% of those reporting over twelve problems demonstrating parental stress at or above the 85th percentile, which is in the abnormal range on the PSI/SF. Furthermore, 82% of parents reporting a high number of problems scored at or above the 85th percentile on the difficult child domain. We also found that the more severe the TBI the greater the financial burden placed upon the family, which in turn increased parental stress. Findings are discussed in detail below in relation to the primary aims of the study.

1 To compare levels of parental stress amongst parents of children with a mild, moderate, and severe TBI, and with stress exhibited by parents of non-injured control children.

Highly significant differences were observed on all four dimensions of the PSI/SF between parents of children with mild, moderate, and severe TBI and parents of controls (p = 0.001). However, there was only a significant difference between the mild, moderate, and severe TBI groups for Parental Distress. Parents of 40 children with TBI (41.2%) and only one parent in the control group were experiencing clinically significant levels of stress (≥ 90th percentile). On the Difficult Child domain 43 children with TBI (44.3%) and no control children scored ≥ 90th percentile which ‘indicates a need for professional assistance’ and suggests that the child demonstrates difficult, defiant, and demanding behaviour and is uncooperative. On the Parent-Child Dysfunctional Interaction domain 39 parents in the TBI group (40.2%) and 5 in the control group (17.2%) scored ≥ 90th percentile indicating a threatened or inadequate bond between parent and child. Parental stress was little altered at twelve month follow-up.

These findings are very similar to those reported by Sokol et al [18] who used the full version of the PSI. They found that 44% of parents of children with TBI within their sample had high stress, with scores at or above the 80th percentile Similarly, Perrot et al [27] found that children with TBI caused their parents more stress than their siblings.

2 To compare the general and psychological health of parents in the TBI and control groups.

There was a statistically significant difference between the mild, moderate, severe, and control groups for general and psychological health as measured by the GHQ-12 ($p = 0.005$), but no significant difference was observed between the mild, moderate, and severe TBI groups. High scores were obtained for approximately 16% of parents in the TBI group. However, at follow-up, parents in the severe group showed a deterioration in health with 34.8% obtaining high scores. Their high stress levels may have contributed to this deterioration.

In a recent study of distress and depression amongst those caring for adults with moderate to severe TBI, Gillen et al [8] found that half of the 39 mothers (49%) in their group were significantly depressed. They also found that neither time since injury nor injury severity predicted diagnostic status.

3 To examine the relationship between reported problems and parental stress and general health

There was a highly significant relationship between total stress, P-CDI, DC, and PD and the number of problems reported at first interview. The higher the number of problems reported, the greater the parental stress. A significant relationship was also observed between parental health as measured on the GHQ-12 and number of problems reported. Emotional problems were reported by three quarters of parents in each of the TBI groups. Counter-intuitively, two thirds of children in the control group had at least one emotional problem. This finding was influenced by the large number of control children (52%) described by their parents as having mood fluctuations, and having a bad attitude towards their siblings (38%). In the TBI groups problems of temper, behaviour and mood were frequently reported, implying a group of children consistent with the ‘difficult child’ domain of the PSI/SF. Other researchers have also found a significant relationship between behavioural problems and parental stress [18].

Family problems were reported by 41% of parents in the severe TBI group, 37% in the moderate, and 12% in the mild group. These included financial difficulties, marital problems, change of employment, and family burden.

Of the 924 problems revisited at 12 month follow up, 127 (13.7%) problems had improved but were still significant, 498 (53.9%) had stayed the same, and 75 (8.1%) had got worse. The long-standing nature of these problems is likely to have an impact on parental health and stress.

4 To examine the financial burden a TBI places upon families.

It has been reported that a TBI can place an overwhelming financial burden on families. McMordie [10], in his study of adults with TBI, found that other family members may suffer a reduction in income, need to borrow money, or change their employment. The study described here has shown that parents of a child with TBI are similarly affected.

Despite the considerable burden on family finances, only five families in our sample reported that they had received financial support from Social Services. Three families in the severe group received Social Services benefits intended for carers of disabled people (disabled living allowance, care component). One unemployed single parent of a severely injured child received additional financial support and a grant for extra equipment and appliances. A family with no earned income received a financial loan from Social Services for extra equipment, but used that money to pay off existing debts, and consequently did not obtain the extra items which the injured child needed. Most of the families involved with Social Services reported that staff were not well informed about the consequences of a head injury, and that although systems are in place to assist children with physical disabilities it is difficult to receive help for children with cognitive and behavioural impairments.

5 To examine information and follow-up requirements

We found that regardless of injury severity, approximately one third of families claimed that no information was given to them by the hospital after a head injury. Over 70% of families, regardless of injury severity, had unmet information needs. It was notable that 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). Of those in the professional and managerial groups two mothers were seeing a private counsellor, and two children received rehabilitation which was paid for by private insurance policies. Such parents may be better equipped to seek out the information they need, and be more likely to ask for information from medical staff.

Many parents reported that they were unprepared for the long-term consequences of a TBI and many parents said they would have liked information on what to expect. Parental requirements may be summed up by the response of one mother coping as a single parent with a severely injured boy interviewed 6 months after the accident: *'I received no follow-up from the hospital. I would have liked him to have had an assessment. I need information on how to get help for (*child*) and how I can claim extra benefits to care for him. There should be* *home visits to see how parents are getting on with the child, I've been just left to get on with it. No-one tells you what to expect. I want to know what he will be like and how to deal with it.'*

The families with a severely injured child had the greatest need for family support of the three groups, but few had received any. Many of these parents welcomed the interview as an opportunity to air their concerns and unanswered questions, even those who were interviewed some years after the injury had occurred. All of the families who required support or someone to talk to were referred to the Brain Injury Liaison Nurse attached to this project. She provided parents with an information pack on TBI which is produced by the Children's Brain Injury Trust in the UK. She also discussed concerns with parents, and wherever possible referred them to a consultant community paediatrician . However, this person did not come fully into post until late in the study, and many referrals did not take place until after the second interviews. Consequently such interventions appear to have had little impact on symptomatic or problem status at second interview.

Several authors have highlighted the need for clear and timely information to be made available to carers of children and adults following TBI [28-30], yet these findings do not appear to have been widely applied to hospital practice. It is also known that parents have a considerable need for support, advice and counselling following their child's TBI [31], to prepare them for the difficulties and problems which may lie ahead. However, these needs are clearly not always met.

6 To identify potential causes of parental stress and recommend ways in which this may be reduced and services improved for parents of a child with TBI.

Serious TBI in a child is likely to have consequences for the family in terms of burden of care and emotional adjustment [32, 33]. The study described here has identified numerous factors which may contribute to the already stressful situation of having a child with a TBI. These findings provide clues to the potential causes of parental stress. Many parents had unmet information requirements and felt ‘in the dark’ about what to expect and what to do about it. This uncertainty may, in turn, lead to worry and additional stress. Not all children received follow-up after hospital discharge, even those with severe TBI may be discharged to parents without any follow-up. Parents are expected to assume the role of carer almost by default, yet many are not adequately prepared for this role, and many more are not offered support. Added to this, the majority of parents in our sample reported reduced opportunities for their own leisure activities and hobbies, so that they were unable to take a break from the role of carer to re-charge their batteries. For the 23% who were single parent families, the burden was even greater.

We found that some families had got into financial difficulties following the injury, as they were on low incomes, or on state benefits before the accident, and after the TBI found themselves with additional expenditure and transport costs to meet. This is an area where early assessment and advice from clinicians could help to avoid later problems. A liaison nurse able to link health and social services and to liaise with employers would be particularly beneficial to help prevent financial hardship.

It is recommended that parents are given clear, written information when their child has a TBI, with the opportunity to discuss issues with a specialist knowledgeable in brain injury. Information packs on paediatric TBI already exist, such as those produced by the Children’s Brain Injury Trust, and these are now being given to parents by staff in the paediatric intensive care unit in North Staffordshire. Parents should also be advised of the benefits and financial assistance that may be available to them, and should be offered support and counselling. A brain injury liaison nurse or similar person should ideally act as a point of contact for parents who have concerns or need help.

Implications for future research

Future research should focus on the causes of parental stress and the provision of services which support caregivers and reduce their stress. Interventions such as early advice, support, and counselling for parents should be evaluated prospectively to establish whether such a programme reduces the likelihood of parental stress and family burden.

Limitations of the study

It is possible that some of the parents in our study group, particularly in the mild group, agreed to take part because they had particular concerns about their child following the TBI. Similarly, some of the parents in the control group may have agreed to take part because they too had concerns about their child.

We did not collect data on parental income or parental educational level as this was not approved by the Local Ethics Committee. The ICIDH measure of economic status could not be reliably scored retrospectively, so it was not possible to measure the change in economic status from pre-to post-TBI.

Children in the TBI group were interviewed at different times post-injury. Only 15 children were interviewed within one year of injury and when divided into severity groups the numbers were too small for separate analysis. However, for the group as a whole we did not observe any significant changes over the 12 month follow-up, even several years post-injury parents were exhibiting significant stress.

The Parenting Stress Index was standardised for use with parents of children up to 12 years old. However, in our study the parents of older children had no difficulty relating to it, and found it quick and easy to use. The results correlated well with self-reported problems, and the percentage of parents obtaining high scores was similar to that found in previous studies.

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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 *Demographics and injury characteristics*

Variable	**Mild** **n = 49**	**Moderate** **n = 19**	**Severe** **n= 29**	**All TBI** **n = 97**	**Control** **n = 31**
First interview: n=	49	19	29	97	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	
No. problems reported interview 1					
Mean	9.14	10.95	15.21	11.31	5.58
SD	5.74	6.39	6.31	6.54	4.76
Second interview: n=	43	17	26	86	21
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 within 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%)	
Other	6 (12.2%)	6 (31.6%)	3 (10.3%)	15 (15.5%)	
Total	49 (100%)	19 (100%)	29 (100%)	97 (100%)	

Table 3 *Parent characteristics at first interview*

Parent Characteristics At First Interview	**Mild n = 49 n (%)**	**Moderate n = 19 n (%)**	**Severe n= 29 n (%)**	**All TBI n = 97 n (%)**	**Control n = 31 n (%)**
Marital Status					
Single parent: never married	6 (12.2)	1 (5.3)	2 (6.9)	9 (9.3)	1 (3.2)
Divorced/separated: single parent	10 (20.4)	1 (5.3)	8 (27.6)	19 (19.6)	5 (16.1)
Married: living together	28 (57.1)	17 (89.5)	18 (62.1)	63 (64.9)	20 (64.5)
Unmarried: living with partner	5 (10.2)	0 (0)	1 (3.4)	6 (6.2)	5 (16.1)
Total	49 (100)	19 (100)	29 (100)	97 (100)	31 (100)
Primary Carer: number female	48 (98)	19 (100)	29 (100)	96 (99)	30 (96.8)
Employment Category: Primary Carer					
Professional	3 (6.1)	2 (10.5)	4 (13.8)	9 (9.3)	7 (22.6)
Managerial	4 (8.2)	2 (10.5)	1 (3.4)	7 (7.2)	0 (0)
Technical, Supervisory	6 (12.2)	1 (5.3)	2 (6.9)	9 (9.3)	2 (6.5)
Clerical	4 (8.2)	2 (10.5)	2 (6.9)	8 (8.2)	2 (6.5)
Skilled workers	3 (6.1)	1 (5.3)	2 (6.9)	6 (6.2)	1 (3.2)
Unskilled workers	12 (24.5)	5 (26.3)	8 (27.6)	25 (25.8)	11 (35.5)
Home-maker	10 (20.4)	3 (15.8)	9 (31.0)	22 (22.7)	4 (12.9)
Unemployed, Student	6 (12.2)	3 (15.8)	1 (3.4)	9 (9.3)	0 (0)
Unknown	1 (2.0)	0 (0)	0 (0)	1 (1.0)	4 (12.9
Total	49 (100)	19 (100)	29 (100)	97 (100)	31 (100)
Economic Self-sufficiency of Family					
Wealthy	2 (4.2)	0 (0)	0 (0)	2 (2.1)	0 (0)
Comfortably off	5 (10.2)	2 (10.5)	4 (13.8)	11 (11.3)	9 (29.0)
Fully self-sufficient	27 (55.1)	11 (57.9)	12 (41.4)	50 (51.5)	13 (41.9)
Adjusted self-sufficiency	5 (10.2)	4 (21.1)	5 (17.2)	14 (14.4)	1 (3.2)
Precariously self-sufficient	10 (20.4)	1 (5.3)	7 (24.1)	18 (18.6)	8 (25.8)
Impoverished	0 (0)	1 (5.3)	0 (0)	1 (1.0)	0 (0)
Economically Inactive	0 (0)	0 (0)	1 (3.4)	1 (1.0)	0 (0)
Total	49 (100)	19 (100)	29 (100)	97 (100)	31 (100)

Table 4 *Problems most frequently reported by parents at first interview*

Problem Category	**Mild** **No. reporting** **N = 49 (%)**	**Moderate** **No. reporting** **N = 19 (%)**	**Severe** **No. reporting** **N = 29 (%)**	**Controls** **No. reporting** **N = 31 (%)**
Emotional Problems				
Attitude to siblings#	15 (38.5%)	5 (29.4%)	10 (41.7%)	11 (37.9%)
Behaviour	19 (38.8%)	9 (47.4%)	11 (37.9%)	1 (3.2%)
Mood fluctuations	30 (61.2%)	8 (42.1%)	18 (62.1%)	16 (51.6%)
Temper	29 (59.2%)	14 (73.4%)	17 (58.6%)	9 (29.0%)
No. reporting Emotional problems	36 (73.5%)	15 (78.9%)	22 (75.9%)	20 (64.5%)
Physical Problems				
Headaches	32 (65.3%)	13 (68.4%)	18 (62.1%)	13 (41.9%)
Sleep	9 (18.4%)	8 (42.1%)	10 (34.5%)	2 (6.5%)
Speech	6 (12.2%)	3 (18.8%)	11 (37.9%)	0 (0%)
Tiredness	15 (30.6%)	3 (15.8%)	12 (41.4%)	9 (29.0%)
Vision	12 (24.5%)	5 (26.3%)	10 (34.5%)	3 (9.7%)
No. reporting Physical problems	34 (69.4%)	13 (68.4%)	22 (75.9%)	13 (41.9%)
Intellectual Problems				
Concentration	29 (59.2%)	9 (47.4%)	21 (72.4%)	13 (41.9%)
Learning*	12 (26.7%)	5 (31.3%)	14 (66.7%)	3 (10.7%)
Memory	20 (40.8%)	8 (42.1%)	15 (51.7%)	10 (32.3%)
Schoolwork*	18 (40.0%)	7 (43.8%)	8 (38.1%)	5 (17.9%)
No. reporting Intellectual Problems	32 (65.3%)	11 (57.9%)	23 (79.3%)	15 (48.4%)
Family problems				
Family problems	6 (12.2%)	7 (36.8%)	12 (41.4%)	1 (3.2%)
Other Problems				
Insurance claim	2 (4.1%)	0 (0%)	12 (57.1%)	N/A
Follow-up	10 (20.4%)	4 (21.1%)	5 (17.2%)	N/A
Information needs	4 (8.2%)	2 (10.5%)	4 (13.8%)	N/A
No. reporting Other Problems	13 (26.5%)	6 (31.6%)	16 (55.2%)	N/A

* 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.

For the problem of 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 5 *Parental GHQ-12 scores for first and second interviews*

Interview Number	**Mild**	**Moderate**	**Severe**	**Control**
Interview 1: n=	47	18	28	18
Mean score.	12.28	13.56	14.57	9.10
Median score	12.0	12.0	13.0	9.0
SD	4.84	7.5	4.67	2.67
Range	5 - 29	6 - 35	7 - 28	5 - 14
Interview 1 Number (%) Scoring ≥18	7 (14.9)	3 (16.7)	5 (17.9)	0 (0)
Interview 2: n=	42	16	23	20
Mean score.	12.17	11.63	15.61	9.80
Median score	11.0	11.5	12.0	10.5
SD	6.45	3.03	6.41	2.63
Range	2 - 34	8 - 19	7 - 31	5 - 15
Interview 2 Number (%) Scoring ≥18	6 (14.3)	1 (6.3%)	8 (34.8)	0 (0)

Table 6: *Parental Stress measured by the Parenting Stress Index (PSI/SF): Interviews 1 and 2*

PSI/SF Subscale	**Mild**	**Moderate**	**Severe**	**Control**
Interview 1: n=	**48**	**19**	**29**	**29**
Total Stress				
Mean % Score	65.31	60.63	78.07	42.24
SD	32.46	32.46	27.91	29.28
Number (%) scoring ≥ 90th Percentile	16 (33.3%)	7 (36.8%)	17 (58.6%)	1 (3.4%)
Parental Distress				
Mean % Score	50.92	41.84	65.0	35.59
SD	29.21	28.05	29.06	23.28
Number (%) scoring ≥ 90th Percentile	5 (10.4%)	2 (10.5%)	8 (27.6%)	0 (0%)
Parent-child dysfunctional interaction				
Mean % Score	69.23	61.95	76.93	54.48
SD	27.81	29.81	26.23	27.30
Number (%) scoring ≥ 90th Percentile	18 (37.5%)	6 (31.6%)	15 (51.7%)	5 (17.2%)
Difficult Child				
Mean % Score	63.04	69.47	73.66	38.97
SD	33.03	30.93	32.73	26.07
Number (%) scoring ≥ 90th Percentile	19 (39.6%)	7 (36.8%)	17 (58.6%)	0 (0%)
Interview 2: n=	**42**	**16**	**26**	**21**
Total Stress				
Mean % Score	62.21	61.06	78.31	46.5
SD	33.45	31.18	28.64	32.19
Number (%) scoring ≥ 90th Percentile	14 (33.3%)	4 (25%)	13 (50%)	2 (9.6)
Parental Distress				
Mean % Score	49.38	47.44	65.96	40.81
SD	29.77	26.17	26.23	28.45
Number (%) scoring ≥ 90th Percentile	6 (14.3%)	2 (12.5%)	5 (19.2%)	1 (4.8%)
Parent-child dysfunctional interaction				
Mean % Score	69.89	63.25	78.54	55.71
SD	30.02	29.80	28.02	31.23
Number (%) scoring ≥ 90th Percentile	17 (40.5%)	6 (37.5%)	17 (65.4%)	3 (14.3%)
Difficult Child				
Mean % Score	60.52	65.44	71.73	40.67
SD	31.52	30.73	31.01	27.72
Number (%) scoring ≥ 90th Percentile	14 (33.3%)	4 (25%)	10 (38.5%)	1 (4.8%)

Table 7: Relationships between problem reporting and parental stress and problem reporting and parental health – all parents (TBI and control)

Parental Assessment	**Problem Band 1 No. (%)**	**Problem Band 2 No. (%)**	**Problem Band 3 No. (%)**	**Pearson X^2 (df = 2)**	**Level of Significance**
PSI/SF score (n=125)					
Number in problem band:	44	37	44		
≥ 85%: Total stress	1 (2.3)	11 (29.7)	32 (72.7)	48.91	p = 0.0001
≥ 85%: Parent-child dysfunctional interaction	5 (11.4)	13 (35.1)	29 (65.9)	28.03	p = 0.0001
≥ 85%: Difficult child	1 (2.3)	11 (29.7)	36 (81.8)	60.52	p = 0.0001
≥ 85%: Parental Distress	1 (2.3)	9 (24.3)	12 (27.3)	11.12	p = 0.004
GHQ-12 (n = 115*)*					
Number in problem band:	36	36	43		
GHQ-12 score ≥ 18	0 (0)	7 (19.4)	8 (18.6)	7.87	P = 0.02

Table 8: Financial burden on the family by severity of injury

Changes following TBI	MILD N = 49	MODERATE N = 19	SEVERE N = 29
Time off Work	22 (45%)	11 (57.9%)	23 (79.3%)
Lost Income	15 (30.6%)	8 (42.1%)	20 (69%)
Lost Job	5 (10.2%)	1 (5.3%)	9 (31%)
Changed Hours	3 (6%)	2 (10.5%)	6 (20.7%)
Time off taken as compassionate leave*	6 (27.3%)	2 (18.2%)	5 (21.7%)
Time off taken as holiday*	1 (4.5%)	1 (9.1%)	3 (13%)
Time off taken unpaid*	15 (68.2%)	8 (72.7%)	14 (60.9%)
Time off taken as sick leave*	0	0	1 (4.3%)
Additional expenditure	12 (24.5%)	9 (47.4%)	19 (65.5%)
Additional transport costs	10 (20.4%)	5 (26.3%)	20 (69%)
Moved house due to TBI	3 (6.1%)	0	3 (10.3%)
Additional state benefits received	1 (2.0%)	0	4 (13.8%)

*as a percentage of those who took time off work