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A 10 YEAR FOLLOW-UP STUDY OF CHILDREN WITH
HEAD INJURIES: PSYCHOSOCIAL ADJUSTMENT

LYNN GERVAIS

in partial fulfillment of the
degree requirements for the
Master of Arts.

Carleton University, Ottawa, Canada.
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"A 10 Year Follow-up Study of Children with Head Injuries: Psychosocial Adjustment"

submitted by

Lynn Gervais

in partial fulfilment of the requirements for the degree of

Master of Arts

Chairman, Department of Psychology

Thesis supervisor

Carleton University

February 1996
ABSTRACT

Extensive evidence clearly demonstrates that psychosocial maladjustment is one of the major and most devastating sequelae of adult head injury. In consideration of the limited data concerning the long-term psychosocial impact of such an injury in children and adolescents, this thesis addresses the question of psychosocial outcome of children 10 years after sustaining a mild, moderate, or a severe head injury. The Sickness Impact Profile (SIP), developed to assess changes in daily activities as a function of health, was administered to a group of young adults in order to investigate the psychosocial adjustment as determined by the outcome measure of the questionnaire. Using hierarchical regression analysis, outcome seemed without correlation to socioeconomic status, age at injury, and severity of injury.
ACKNOWLEDGEMENTS

I would like to thank my advisors Dr. W. Jones and Dr. R. Knights for their time, patience, and support. Thank you to my committee for their direction. A special thank you to Dr. A. Robertson for his friendly advice and motivation. And of course, this would not have been possible if not for the support of my family and friends. Fortunately for me, there are too many to acknowledge here but I must make an exception for Michelle and Ryan, - thank you so very much - I love you.
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A 10 Year Follow-Up Study of Children With
Head Injuries: Psychosocial Adjustment

It is estimated that each year, 29,000 children from
birth to 19 years of age are permanently disabled due to
moderate or severe traumatic head injury (Division of Injury
Control, 1990). Sudden physical injury to the brain may
cause, in addition to sensory and motor disabilities,
significant alterations in cognition, emotion, and
communication (Asarnow, Satz, Light, Lewis, & Neumann, 1991;
Capruso & Levin, 1992; Filley, Cranberg, Alexander, & Hart,
1987; Levin, Grafman & Eisenberg, 1987; Jaffe, Fay,
Polissar, Martin, Shurtleff, Rivarz, & Winn, 1992; Jaffe,
Polissar, Fay, & Liao, 1995; Knights, Ivan, Ventureyra,
Bentivoglio, Stoddart, Winogron, & Bawden, 1991; Lezak,
1978, 1987; Prigatano, 1986; Scott-Jupp, Marlow, Seddon, &
Rosenbloom, 1992; Winogron, Knights & Bawden, 1984; Wood,
1990). Further, many of the victims of head injury also
incur psychosocial problems, that is alterations in social
interaction and functioning, and interpersonal
communication, which may create the greatest obstacle to the
person's capacity to function independently (Giacino &
Zasler, 1995; Lezak, 1978, 1987; Waaland, Burns, & Cockrell,
1993).
In order to quantify the degree of recovery of psychosocial functioning over the course of time, further information on the long-term outcomes is necessary. The present investigation is a follow-up of a study by Knights et al. (1991) in an attempt to identify psychosocial consequences of the 76 children who were admitted to the Children's Hospital of Eastern Ontario presenting varying degrees of head trauma.

Knights et al. (1991) examined the effects of head injury in children with respect to the specific nature of the ability deficits, the rate of improvement over time, and the relationship of the severity of injury to subsequent neuropsychological and behavioral functioning.

The children were administered an extensive battery of neuropsychological tests including intelligence and achievement assessments. The first testing occurred just prior to discharge. The second assessment occurred three months later, and the third assessment occurred nine months after the initial assessment. In addition, each child's behaviour was rated three times by their teachers and parents on the Connors Behaviour Rating Scales. One year after head injury, the parents were asked to complete a behavioral checklist to indicate differences in the child's behaviour compared to that before the injury. The results of Knights et al. (1991) showed impairments of cognitive and motor skills and problems with behavioral adjustment. With
respect to behaviour ratings, in the mild and moderate injury group very few had behavioral change while in the severe group, approximately 90 percent had learning or adjustment problems.

Brain trauma is a process with multiple variables, including type and intensity of injury, pathological reactions to the injury that may increase over a period of time, and processes of healing and adaptation. As might be expected, the resulting neuropsychological consequences may be extremely variable and may include motor, cognitive, behavioral, sensory, interpersonal and communication disorders. Language disorders may be expressive, receptive, or mixed and deficits may occur in naming, word retrieval, verbal organization, comprehension of rapidly presented or large amounts of verbal information, comprehension of verbal abstractions, efficient verbal learning, and effective discourse (Ylvisaker, 1986).

Vision and hearing can both be affected following brain injury. Visual deficits can result from injury to the optic nerve, involvement of cranial nerves I, II - VII, cerebellar injury, or lesions affecting the visual cortical pathway. Hearing loss is usually the result of a fracture of the temporal bone (Michaud, Duhaime, & Batshaw, 1993).

Changes in personality and behaviour are not unusual. The most common behaviour problems are aggression, poor anger control, hyperactivity, decreased attention, and
social withdrawal (Filley et al., 1987).

Spasticity, incoordination, and ataxia are the most common motor disabilities following traumatic brain injury (Brink, Garrett, Hale, Woo-Sam, & Nickle, 1970).

Numerous cognitive processes may be disrupted, including cognitive flexibility, concept formation, problem solving, and information analysis. Learning problems are often evident and concrete thinking, rigidity of thinking, and memory problems are prominent (Stern & Stern, 1985). Even with good recovery there may be subtle cognitive deficits that may significantly affect performance in school (Jaffe et al., 1992).

There are many objective and standardized measures of neuropsychologic functioning to assess cognitive abilities following head injury, for example, learning, memory, and reasoning (Table 1). Unless direct damage to the left hemisphere has been sustained, most head injured patients have little or no difficulty with verbal tests or tests of constructional abilities and perceptual accuracy that are uncomplicated by memory, organization, or speed requirements (Lezak, 1995).

Neuropsychologic tests do not, however, directly address important executive functions or daily living skills such as goal setting, planning, or ability to adapt to changing environmental conditions, and making and maintaining close social relationships. Deficits in these areas may not
Table 1. Domains of Cognition and Selected Neuropsychological Tests

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<tr>
<th>Abilities Assessed</th>
<th>Neuropsychological Tests*</th>
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<tr>
<td><strong>Memory</strong></td>
<td>Wechsler Memory Scale-Revised</td>
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<td></td>
<td>California Verbal Learning Test</td>
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<td></td>
<td>Galveston Orientation and Amnesia Test</td>
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<td>Children’s Orientation and Amnesia Test</td>
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<td><strong>Intelligence</strong></td>
<td>WAIS-R</td>
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<tr>
<td>(Verbal IQ) &amp; (Performance IQ)</td>
<td>Wechsler Intelligence Scale for Children-Revised (WISC-R)</td>
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<tr>
<td><strong>Language</strong></td>
<td>Boston Naming Test</td>
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<td>Pegboard Tasks</td>
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<td>Finger Oscillation</td>
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<td><strong>Executive functioning</strong></td>
<td>Wisconsin Card Sorting Test</td>
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<td>Category Test</td>
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<td><strong>Academic Performance</strong></td>
<td>Wide Range Achievement Test-R</td>
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<tr>
<td></td>
<td>(Reading, Spelling, and Arithmetic Subtests)</td>
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*Listed are some commonly used neuropsychologic instruments.
become evident unless assessments are geared to eliciting such impairments. Further, these functions and skills cannot be equated with psychometric intelligence. In fact, many head injured individuals can perform adequately on a neuropsychological test battery (Lezak, 1995). For example, Levin, Goldstein, and High (1988) found that many brain injured adults achieved score patterns on the Wechsler Adult Intelligence Scale-Revised (WAIS-R) well within the normal range on tests of most cognitive functions. It appears then, that most standardized measures of cognitive ability may not adequately reflect long-term psychosocial deficits resulting from head injury.

There is a body of literature that describes a growing awareness of continuing psychosocial deficits in adults following brain injury (Brooks, 1986, 1992; Dikmen & Machamer, 1995; Dikmen, Temkin, Machamer, Holubkov, Fraser, & Winn, 1994; Hendryx, 1989; Lezak, 1987; McLean, Dikmen, & Temkin, 1993; Oddy, Humphrey, & Uttley, 1978; Prigatano, 1987; Rappaport, Herrero-Backe, Rappaport, & Winterfield, 1989; Thomsen, 1984). The evidence clearly demonstrates that psychosocial maladjustment in adults is one of the major and most devastating sequelae of head injury (Brooks, 1984; Bruce, 1990; Hendryx, 1989; Levin, Eisenberg, & Benton, 1989; Lezak, 1978, 1987; Oddy, Coughlan, Tyerman, & Jenkins, 1985; Thomsen, 1984; Weddell, Oddy, & Jenkins, 1980). Regardless of the etiology, nature of preinjury
relationships, and length of time postinjury, brain injury appears to result in significant change in psychosocial adjustment as perceived by the families of head-injured individuals (Hendryx, 1989; Oddy et al., 1978; Thomsen, 1974), the individuals themselves (Hendryx, 1989; Temkin, Dikmen, Machamer, & McLean, 1989), and by rehabilitation therapists (Prigatano, 1986).

The majority of severely head-injured adults appear to experience disruptions to everyday activities, marked changes in occupational status, leisure activities, and family life. Loss of social contacts and social isolation present the most serious problems (Costeff, Groswassar, & Goldstein, 1990; Kriel, Krach, Bergland, & Panser, 1988; Lezak, 1978, 1987; Morton & Wehman, 1995; Oddy et al., 1978; Varney & Menefee, 1993). In general, it was noted that severely head-injured adults tend to live without extensive social contact and most were less successful in social endeavours than they were prior to injury. In many cases, this change in social contacts creates loneliness and depression (Lezak, 1995; Morton & Wehman, 1995).

Measures of health status, or quality of life, have been used to assess critical aspects of patient outcome, such as psychosocial adjustment. Studies vary greatly on how psychosocial outcome is measured and in the source of information. Measures of outcome range from brief, open-ended interviews with poorly defined criteria for
psychosocial problems and no normative data to standardized inventories with normative data and validated criteria for psychosocial problems (Asarnow et al., 1991).

There are few objective and standardized measures of psychosocial functioning that are sensitive to alterations in the daily activities of people after a head injury. An increasing amount of interest in studying the social outcome of individuals after head injury has emphasized a need for satisfactory measures of social outcome. Numerous health status measures have been developed in the last several years that measure various aspects of social functioning. Most scales, however, either cover different social domains (e.g., marital relationships, leisure pursuits and finances) or include overlapping concepts and areas such as social support, social attachments, and social competence that are measured with varying emphasis, depending on the scale. Some of the more common indices of social and behavioral outcome include the Social Scales such as Bond's Social Scale (BSS), Katz Adjustment Scales (KAS) for relatives and subject, the Glasgow Outcome Scale (GOS), Child Behaviour Check List (CBCL) for both parent and teacher ratings, Minnesota Multiphasic Personality Inventory (MMPI), Myers-Briggs, Family Environment Scale (FES), Home Environment Questionnaire, and subjective reports. The BSS was specifically devised for rating social outcome after head injury and consists of six items rated on three to five
point scales, based on information obtained from both subject and informant concerning the effects of injury on work status, leisure activities, family cohesion, sexual behaviour and the development of criminality or abuse (Bond, 1975). The GOS was specifically designed to measure overall outcome after head injury and rates on a five point scale ranging from death to good recovery (Jennett & Bond, 1975). The main drawback of both the BSS and the GOS is the narrow range of ratings produced, allowing little room for the measurement of change.

Typically, the psychosocial functioning of adult patients sustaining head injury has been determined by interviewer rating and only a few studies have examined self-reports of psychosocial problems (McLean, Dikmen, Tikmen, Wyler, & Gale, 1984; Oddy et al., 1978; Thomsen, 1974). A quality of life study conducted two to four years post-injury by Klonoff, Snow, and Costa (1986) focused primarily on subject interviews and self-reports to measure the physical, emotional, and psychosocial characteristics of head injured patients. The self-reported areas of primary dysfunction were psychosocial functioning (specifically social isolation), social role functioning, and leisure and recreation activities. The authors concluded that acute psychosocial sequelae are maintained up to four years post-injury which seriously disrupts quality of life.

Thomsen (1974) noted that lack of social contact was
the main problem of the 50 subjects in his study as most subjects, at four or five months post injury, had lost their pre-injury friends and had little opportunity for making new friends due to spending the majority of their time at home. Ten years later Thomsen (1984) produced a follow-up study on these same subjects and reported that loss of social contact continued to be a problem. Few of the subjects had retained their pre-injury friends, and most had substituted casual acquaintances or made new friends with elderly people. Thomsen noted that, other than social contact, the areas of work and independent living had improved with time.

Hendryx (1989) evaluated perceived psychosocial changes as assessed by family members, 20 patients with moderate to good recovery, and 20 non-brain-injured controls. She found that patients and family members perceived emotional changes after brain injury despite a good recovery as indicated by the Glasgow Coma Outcome Scale.

Lezak (1988) evaluated initially 42 participants a number of times up to five years post injury and found a psychosocial pattern of continuing social dysfunction emerged over the entire follow-up period. The majority of participants had problems with social contact at each follow-up period. At three years post injury, of the 39 who participated, 18 had returned to work or school, but only six were in situations similar to pre-injury status. At 5 years post injury, five of the same
individuals were in psychiatric hospitals, six were in nursing homes, one had served a jail sentence, and 11 had received subsequent head injuries.

In contrast, relatively limited empirical information exists regarding the long-term psychosocial outcomes associated with head injury in childhood or about the process of social readjustment after childhood head injury (Asarnow et al., 1991; Brink et al., 1970; Ewing-Cobbs, Fletcher, & Levin, 1985; Fletcher, Ewing-Cobbs, Miner, Levin, & Eisenberg, 1990; Jaffe et al., 1995; Kriel et al., 1988; McGuire & Rothenberg, 1986; Perrott, Taylor, & Montes, 1991; Ruijs, Keyser, & Gabreels, 1994). Fletcher et al. (1990) examined the adaptive living skills of a group of 45 children, ranging in age from 3 to 15 years of age at injury, who were placed in one of three severity categories using established indices of severity of Glasgow Coma Scale score (GCS), computed tomographic (CT) scan findings, and the duration of impaired consciousness. Fletcher et al. (1990) found that children who had sustained severe head injuries showed substantial declines relative to premorbid expectations in their ability to deal with the day-to-day challenges of life whereas children with mild and moderate injuries did not deviate from average levels. Severe head injury in children was associated with declines in adaptive behaviour. However, mild and moderate injury in children was not associated with a tendency to more impairment in
behavioral functioning at the time of injury.

In an investigation of the pattern of change in neurobehavioral, academic, and "real world" functioning over the course of three years in children between the ages of 6 and 15 years at time of injury, Jaffe et al. (1995) found that injury severity exerts a significant influence over the child's recovery during the first three years. With respect to neurobehavioral functioning, moderately and severely injured children showed substantial deficits of varying magnitude in most intellectual, neuropsychological, and academic areas. On the other hand, mildly injured children showed negligible impact of injury on neurobehavioral functioning. Measures of "real world" skills, however, did not show a pattern of long-term, chronic deficit. Mildly and moderately injured children showed little initial deficit as opposed to the severely injured children who showed substantial deficit. However, at one and three years, none of the groups of head injured children showed significant deficits. Only eating/meal preparation, dressing, time and punctuality, and work skills showed severity-related differences in mean performance across three years.

In accordance with previous studies, Jaffe et al. (1995) suggest that moderately and severely injured children can expect to experience continuing intellectual, neuropsychological, and academic deficits as a result of
their injuries. Although this study provided the opportunity to better understand the history of recovery, the emphasis was on cognitive outcomes as measured by intellectual and neuropsychological test batteries. The time of observation was only within the first three years of head injury and findings offered little information with regard to the very long term psychosocial aspects of head injured children as they become adults.

Kriel et al. (1988) interviewed 28 severely head injured patients (13–18 years at time of injury), two to 11 years after injury. The authors developed and used a 21 item questionnaire which included questions on educational level, current living situation, employment data, treatment for substance abuse, marital status, use of leisure time, and status of social relationships. At follow-up, patients achieved lower educational levels and required special educational services compared to the reference population. In general, it was found that patients lived in isolation without extensive social contact. The authors reported that the problems encountered by head injured teenagers as they entered young adulthood included having to deal with new learning problems, a changed self-perception resulting from the loss of academic status, impaired comprehension of oral language, difficulty establishing an independent identity, and impaired abilities to socially interact.

Although the use of a general measure to evaluate daily
activities in head-injured patients has the advantage of facilitating comparison of results within and across disabilities, a measure specific to head injury would be expected to be more responsive to the changes likely to occur in head-injured patients because it was designed to address activities specifically related to the head-injured population. The Sickness Impact Profile (SIP) has gained wide acceptance through its use in studies of various conditions including cardiac arrest, burns, and chronic obstructive pulmonary disease (Bergner, Bobbitt, Pollard, Martin, & Gilson, 1976). More recently, researchers have effectively utilized the SIP for assessing psychosocial dysfunction following traumatic head injury in adults (Dikmen, Machamer, & Temkin, 1993; Klonoff, Costa, & Snow, 1985; Temkin et al., 1989). Temkin et al., (1989) investigated the suitability of the SIP as modified by the addition of items, deletion of others, and reweighting areas of function so as to, in theory, make the SIP more sensitive to head injury. In practice, however, the modifications failed to result in improvements sufficiently large or sufficiently consistent to provide a practical advantage over the standard SIP. Further, they conclude the standard SIP performs well as a measure of psychosocial functioning following head injury.

The SIP is a broad-based behavioral measure of psychosocial functioning for which good reliability and
validity data are available (Bergner, Bobbitt, Carter, & Gilson, 1981; Bergner et al., 1976). The SIP was designed to assess the effect of sickness on the performance of daily activities and presents the respondent's perception of how her/his illness has altered her/his behaviour in the different areas of living assessed. Three summary scores may be calculated: 1) the physical scale reflects endorsements on the ambulation, mobility and body care, and movement subscales; 2) the psychosocial scale reflects endorsements on social interaction, communication, alertness behaviour and emotional behaviour; and 3) the total score reflects endorsements on all 12 areas of living.

The SIP questionnaire may be scored at several levels of functioning providing category scores, two dimension scores, and overall scores. Subjects are instructed to respond to only those items in the SIP that describe them on a given day and are related to her/his health. Based on a consensus of health care consumers, each item in the instrument is assigned a weight or scale value indicating its relative severity of dysfunction.

The SIP was designed in order to be either interviewer-administered or self-administered and has demonstrated an acceptable level of overall validity. Self-administration of the SIP has also been tested as a mail-delivered SIP and again, has demonstrated an acceptable level of overall reliability.
There is little doubt that childhood head injury differs from adult head injury (Boll & Bryant, 1988). Children and adolescent head injury survivors present special problems due to the variety of their presentations and the complexity of the interplay between developmental, psychological, and family factors. Numerous studies have compared cognitive outcome in head injured children with that of adults and most of them conclude the age of the individual at the time of injury appears to have an important bearing on the eventual functional outcome (Ruijs et al., 1994). That is, the lower the age of the victim, the better the recovery of function (Braakman, Gelpke, Habbema, Maas, & Minderhoud, 1980; Levin, 1992; Ewing-Cobbs, Miner, Fletcher, & Levin, 1989; Chadwick, Rutter, Thompson, & Shaffer, 1981). It is not necessarily that the child is more resilient to brain damage than the adult, but rather, that the kind of brain damage that prevents the development of a skill appears to be different from the damage that disrupts the maintenance of that skill, once acquired. Two of the most important aspects of difference are that a child is a growing organism, and that functional development is incomplete (Gans, Mann, & Ylvisaker, 1990).

In normal development, functions evolve and develop in an integrated and/or synchronous fashion. A normal child grows up with the ability to think, solve problems, learn, and enjoy life. Development involves both losing irrelevant
older functions in order to increase control over cognitive, sensory, and motor functions (Dennis, 1988). Injury to the brain may impair the development of the child and delayed development in one function can have a cumulative effect on many subsequently developing functions.

Head injury during childhood or adolescence may impair expected and normative resolution of developmental tasks. Under normal circumstances, children are dependent on their parents. Head injured children, however, are unusually dependent on their families. Also, while injured children are recovering, noninjured children are continuing on their undisturbed developmental course, establishing more highly integrated intellectual and neuropsychological skills. Thus, for injured children and adolescents, it is insufficient for them merely to recover the specific behaviours and skills that were disrupted by the head injury. Full recovery implies reestablishing academic, intellectual, and neurocognitive parity with peers. This requires not only reacquisition of those skills that were impaired as a direct consequence of the injury, but also an accelerated acquisition of skills across all developmental and academic areas. These factors combine with common psychosocial deficits, such as disinhibition and impaired social judgment, to block normal social experiences and development. For example, autonomous functioning and independence, both of which are essential to psychosocial
maturation, may be set back by long periods spent as a patient and away from peer groups. Given this, the head injured adolescent often does not fit well into her/his previous peer group because of diminished social skills. Consequently, the individual may suffer a significant decrease in her/his friendships and social support leading to prolonged feelings of loneliness and social isolation. A further consequence may be a lack of opportunity for establishing new social contacts and friends (Gans et al., 1990; Morton & Wehman, 1995).

In terms of totality of function in the adult, it seems clear that there is a genetic blueprint sufficient to sketch the outline of a fully functional central nervous system (CNS). Less well understood are the mechanisms underlying recovery of CNS functions with respect to the developing brain and neuroplasticity (Bruce, 1990). Given this, the overall difference between brain trauma in children and adults would seem to be the difference between damage to a developing and developed brain. This suggests the child suffers impairment of the ability to acquire and develop new mental functions of any kind, while the adult suffers impairment of specific functions previously acquired.

A recurring question in considering recovery from brain injury is the possible contribution of age of the individual at the time of the insult. Jennett, Teasdale, & Knill-Jones (1975) note that age and psychosocial status are two factors
independent of the episode of brain damage likely to influence recovery. The authors note that "...age determines the possibility of good recovery after different degrees of coma; younger patients can withstand longer coma and still retain the capacity to recover (p. 311-312)".

Evidence from animal experiments has tended to suggest that brain lesions in young animals are generally better tolerated than those sustained at a later age, leading to the widely held view that recovery from brain damage is greatest when the damage occurs early in life (Kennard, 1936; Lennenberg, 1967). It is believed that children recover more quickly and completely than adults from comparable injuries and that a child's prognosis for recovery is good. Recovery is generally more successful in younger people because the plasticity of the nervous system and capacity of residual intact brain tissue to subsume the functions of damaged tissue make significant contributions to good functional recovery (McClelland, 1988). In other words, as age increases, the probability of favourable prognosis decreases (Jennett, Teasdale, Braakman, Minderhoud, Heiden, & Kurze, 1979; Jennett, Teasdale, Braakman, Minderhoud, & Knill-Jones, 1976). Jennett et al. (1975) note, however, that the effect of age is related only to various age groupings and it is unclear whether or not the influence of age is linear.

Knights et al. (1991) discussed the issue of the
relationship between age at the time of injury and potential differences in recovery and note, in general, it is unclear whether younger children recover faster or more completely than their older counterparts. The authors suggest, from clinical observation, that younger children make a more rapid and complete recovery and further suggest there is little difference in the sequelae of mild and moderate head injury in children. How much of the improved outcome in childhood is a factor of the mechanism of underlying injury and the extent of the primary damage and how much is a function of the plasticity and recoverability of the younger brain remains unclear.

Although the plasticity of the developing brain often allows a dramatic recovery of function (Chadwick et al., 1981) and children may recover quickly after CHI, many of them nevertheless exhibit persisting problems of a psychosocial nature, even in the absence of clear neurological abnormalities (Rimel, Giordani, Barth, Boll, & Jane, 1981; Ruijs, Keyser, & Gabreels, 1990, 1992; Fletcher, Miner, & Ewing-Cobbs, 1987). Consistent with the results of Rutter, Chadwick, Shaffer, & Brown (1980), which emphasizes the psychosocial and neurobehavioral morbidity associated with severe CHI in children, Asarnow et al., (1991) found an excessive rate of behavioral problems as well as impairments in multiple aspects of adaptive functioning at follow-up. In this study, however, children with mild CHI also had an
excessive rate of behaviour problems postaccident but did not have impaired adaptive functioning.

We should also note that other researchers have questioned the idea that recovery from head injury in children is more rapid and complete (Filley et al., 1987; Kolb, 1989). On the one hand, the consequences of head injury seem to be more severe in the older child but, on the other, studies of brain development, plasticity, and behaviour suggest that recovery is not more complete when injury occurs early in the child’s life (Kolb, 1989). As stated by researchers such as Costeff et al (1990) and Kolb (1989), the greater plasticity of the child’s brain may actually be a liability rather than an asset in recovery from brain injury.

Raimondi & Hirschauer (1984), note from clinical experience that some lesions may have more widespread deleterious effects when occurring in infancy (e.g., hydrocephalus) and suggest that poorer outcomes in infants may be due to younger children more often suffering secondary injury. Woods (1980) found that the IQs of children with brain damage in the first year of life were well below average as well as below those of children who suffered brain damage later in life.

Researchers such as Filley et al., (1987) suggest that children six years old or under do not fare as well in terms of social and school/vocational functioning. Perrot,
Taylor, & Montes (1991) found, with few exceptions, that intellectual and cognitive functioning was only slightly diminished in a group of head-injured children compared to siblings. In contrast, behaviour, school performance, and adaptive living skills were all significantly affected. Vilkki, Ahola, Holst, Ohman, Servo, & Heiskanen (1984) demonstrated that age is strongly related to the decline of social activities after closed head injury. The authors suggest that the ability to compensate for subsequent mental impairments in psychosocial activities decreases with age and that young patients may be able to compensate for even severe operational deficits in their social activities.

In general, the effect of age at injury on neurologic outcome is not clear and the results among studies are inconsistent. Outcomes from brain injuries at younger ages have been reported to be better (Braakman et al., 1980; Lennenberg, 1967; Levin, 1992), worse for infants less than 2 years (Mahoney, D'Souza, Haller, Rogers, Epstein, & Freeman, 1983; Raimondi & Hirschauer, 1984; Luerssen, Klauber, & Marshall, 1988), worse for children below age 10 years (Brink, Garrett, Hale, Woo-Sam, & Nickle, 1970) and below age 12 years (Levin, & Eisenberg, 1979; Levin, Eisenberg, Wigg, & Kobayashi, 1982), or no different age effect of children at the time of injury (Berger, Pitts, Lovely, Edwards, & Bartkowsky, 1985).

Available research findings provide some understanding
of the characteristics of children who sustain head injury. Researchers note, however, that prognosis is complicated by the uniqueness of every injury and that the repercussions of brain damage and recovery rates vary with age (Ewing-Cobbs et al., 1989), etiology (Lezak, 1995), severity of injury (Fletcher, Ewing-Cobbs, Miner, Levin, & Eisenberg, 1990; Kay, 1993; Lezak, 1995), lesion site (Lezak, 1995), size of lesion (Lezak, 1995), pre-injury intellectual, physical and mental condition (Stratton & Gregory, 1994), pathophysiologic response of the brain (Bruce, 1990; Pang, 1985), as well as with psychosocial background and status of the patient (Waaland et al., 1993; Rutter, 1981), and the nature of post-injury social and medical support systems (Stratton & Gregory, 1994).

More recently, researchers have begun to elucidate how factors such as socioeconomic status (Brown, Chadwick, Shaffer, Rutter, & Traub, 1981; Rutter et al., 1980), age (Ewing-Cobbs et al., 1989), and severity of injury (Fletcher et al., 1990; Rutter, Chadwick, & Shaffer, 1983) alter patient risk for injury or prognosis for recovery following injury. Background psychosocial factors might be particularly important in families of children involved in accidents when examining the relationship between social and family variables and psychosocial adjustment. For example, a strong relationship has been demonstrated between family financial and psychological resources to adjustment, coping
skills, and patient outcome related to other types of childhood disabilities (Wallander, Varni, Babani, Banis, DeHaan, & Wilcox, 1989). Further, Rutter (1981) noted that brain damage often led to both intellectual impairment and psychiatric disorders, noting, however, that children with brain damage may be disadvantaged in many other ways so that their problems may stem as much from the associated psychosocial deprivation as from the brain pathology.

Socioeconomic status (SES) has been consistently linked to health with individuals higher in the social hierarchy typically enjoying better health than do those of lower-status (Feinstein, 1993). Empirical evidence supports the hypothesis that members of lower-status groups do less well in the health care system as they are disadvantaged not only in their likelihood of being exposed to more stressful life events but also in the resources they have available to cope with those events, such as social support and resilient personality characteristics (Feinstein, 1993; Lichtenstein, Harris, Pedersen, & McClearn, 1993; McLeod & Kessler, 1990). Higher placement in the SES hierarchy diminishes the likelihood that individuals will encounter negative events such as experiencing major financial difficulties, being in a low-status occupation, or experiencing an act of violence (McLeod & Kessler, 1990). Furthermore, individuals higher on the socioeconomic ladder enjoy experiences that accompany higher education and financial autonomy that in turn foster
the development of positive self-perceptions and cognitive flexibility. Thus, individuals at higher socioeconomic level may perceive a stronger sense of control over or have more frequent opportunities to influence the events that affect their lives, compared with people at lower levels.

Individuals lower in the SES hierarchy may have fewer social and psychological resources to cope with stressful life events, that is, they may have fewer opportunities or resources to form, maintain, and access social networks that can buffer the effects of stressful life events and use the least effective coping strategies (McLeod & Kessler, 1990). This may be in part because lower income restricts the choice of physician, health care plan, and treatment option and in part because they are less aware of side effects or any other posttreatment abnormalities.

In summary, hierarchial position can have a direct effect on health as well as indirect effects through SES-related differences in (a) the physical environment in which one lives and works and associated exposure to environmental hazards; (b) the social environment and associated vulnerability to aggression and violence as well as degree of access to social resources and supports; (c) socialization and experiences that influence psychological development, mood, affect, and cognition; and (d) health behaviours such as diet and compliance with medical advice (Adler, Boyce, Chesney, Cohen, Folkman, Kahn, & Syme, 1994).
A three-centre study by Levin et al. (1987), comparing the experience of head injury in three geographically and socioculturally diverse trauma centres disclosed the immense contribution of sociocultural factors. It is, therefore, conceptualized that family socioeconomic status may be an important mediator of adjustment following childhood head injury. SES derives from both social and economic factors. Measures of SES typically incorporate economic status, measured by income, social status, measured by education, and work status, measured by occupation (Dutton & Levine, 1989). The three indicators are interrelated but not fully overlapping variables and SES is typically measured by a single variable, such as income or education. For the purpose of this investigation, SES will be the index originally reported in Knights et al. (1991) study. Using the Blishen Index (Blishen & McRoberts, 1976), occupational status was determined for the head of the household.

Another important injury-related variable which has been evaluated relative to progress is depth and duration of impaired consciousness and coma, typically indicated by early Glasgow Coma Scale (GCS), in children as well as adults (Teasdale and Jennett, 1974). GCS formalizes observations and provides a classification for evaluating impaired consciousness. In other words, GCS allows a more precise comparison of the varying degrees of higher integrative functions in head-injured patients. GCS elicits
responses with a high degree of consistency and has considerably reduced the amount of semantic confusion and subjectivity which surrounds the assessment of unconsciousness. The GCS is based on motor, verbal, and eye opening responses, each being evaluated independently of the other (Table 2). The lowest combined score is 3 and the highest is 15. Patients in coma having GCS scores of 13 to 15 reflect minor injury, scores of 9 to 12 reflect moderate brain injury, and scores of 8 or less are considered to reflect severe brain injury.

Impaired or posttraumatic consciousness is an expression of dysfunction in the brain as a whole and until the development of the GCS, systems for describing patients with impaired consciousness were not consistent and made meaningful interstudy comparisons difficult (Winogron et al., 1984). That is, there was no general agreement about what terms to use, nor were commonly used terms interpreted similarly by different workers. To be generally accepted, a system must be an effective method of describing the various states of impaired consciousness and of identifying responses which can be clearly defined, and each of which can be accurately graded according to a rank order that indicates the degree of dysfunction (Teasdale & Jennett, 1974).

GCS is a measure of cerebral function, and as such, is sensitive to the wide variety of subtle neural impairments.
## Table 2. Three aspects of behavioral response.

<table>
<thead>
<tr>
<th>Function</th>
<th>Response</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Eye Opening</strong></td>
<td>Spontaneous</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>To speech</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>To pain</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>1</td>
</tr>
<tr>
<td><strong>Best Verbal Response</strong></td>
<td>Oriented</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Confused</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Words</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Sounds</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>1</td>
</tr>
<tr>
<td><strong>Best Motor Response</strong></td>
<td>Obeys commands</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Localises pain</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Flexion withdrawal</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Flexion to pain</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Extension to pain</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>1</td>
</tr>
</tbody>
</table>
A wide variety of injuries do not produce homogeneous damage to the brain and measures of severity such as depth of coma, depends more on the functional integrity of specific neural substrates than others. For example, injury with resultant major damage to frontal lobe structures may not be associated with major damage to the brain stem reticular formation, and therefore, may not be reflected in either deep or prolonged coma.

Damage to the frontal cortex is common following brain injury. Typically, this involves abrasions, lacerations, and contusions to tissue on the inferior aspect of the frontal lobes, as inflicted by the rough bony structure that separates the frontal lobes (Stuss & Benson, 1984). Medical consequences of such an injury can be relatively trivial, but can have potential consequences on psychosocial competency, for example, indecisiveness and confused insight (Jennett & Teasdale, 1981; Varney & Menefee, 1993). In the more severe cases, the problem presented by patients with orbital frontal damage is that they have marked personality changes and related problems.

There are limitations to the GCS in that it was developed for adults and the verbal portion can be difficult to apply to young children. Also, the verbal component of the GCS cannot be applied to the intubated patient of any age and because the score is determined by the patient’s best response, focal deficits such as hemiparesis are not
weighted (Michaud, Duhaime, & Batshaw, 1993). Despite these limitations, the GCS is widely accepted in both clinical practice and scientific research as criteria for the severity of injury (Brooks, 1974; Rutter et al., 1980; Winogron et al., 1984).

Knights et al. (1991) established that mild closed head injury (CHI), (GCS scores 13-15) is not associated with long-term effects of CHI and severe pediatric CHI, (GCS scores 8 or less) is associated with persistent, long-term neurobehavioral difficulties. Fletcher & Ewing-Cobbs (1991) state that a classification of injury severity based on GCS scores has prognostic significance but recognize some of the possible limitations of this classification, particularly with regard to moderate injuries. For example, the moderated group, (GCS scores 9-12) tends to be heterogeneous, particularly in regard to type of contusional insult and mass lesion.

In terms of severity of injury, studies following children sustaining severe head injury indicate that increased severity of head injury may well be a contributing factor in determining the psychosocial adjustment in the very long-term with the likelihood of sequelae gradually increasing with the severity of injury (Kriel et al., 1988; Costeff et al., 1990). In general, it was noted that the patients live without extensive social contact and most patients state they are less successful in social endeavour
than they were prior to injury. Investigations of the effects of severity of injury on outcome, then, would suggest that mildly head injured individuals may be relatively spared in terms of psychosocial adjustment problems when compared to their severely head injured counterparts (Asarnow et al., 1991).

The primary goal of the present investigation is to document the psychosocial status of young adults who experienced either a mild, moderate, or severe closed head injury (CHI) during childhood or adolescence, with a view to establishing the potential effects of CHI on psychosocial functioning in adult life. A second goal is to investigate the hypothesis that socioeconomic status, age at injury, and severity of injury predict psychosocial adjustment after CHI.

METHOD:

SUBJECTS:

The participants for this study were obtained from archival records of the Children’s Hospital of Eastern Ontario (CHEO) and were limited to the original 76 individuals who had suffered a head injury during childhood who were admitted to the Children’s Hospital of Eastern Ontario during the years 1981 and 1986 and, who had participated in the Knights et al. (1991) study. Participants ranged in age from 5 years to 17 years at the
time of injury (mean=10.8 years) and two thirds were males. The average SES level was representative of managers in Government, Social Sciences, and Durable goods manufacture. All participants presented varying degrees of severity of brain insult as was rated using the Glasgow Coma Scale (GCS). GCS was assessed on original admission by the admitting physician. The participants were divided into three groups based on the GCS: mild (GCS 13-15), moderate (GCS 8-12), and severe (GCS 7 or less); intracranial pressure (ICP), and coma duration (CD). The mild group included children who were kept in hospital overnight, the moderate group consisted of children who were usually in coma less than one day, and the severe group consisted of children who were managed with therapeutic barbiturate coma.

In the initial three assessments, the child’s parents completed a general information form which included their address and phone number. In addition, the names of other contact persons, such as friends, siblings, and grandparents were listed. This information was used in the current study as a basis for contacting, by telephone, the patient directly or for contacting her/his parents or contact person listed.

MATERIALS:

The Sickness Impact Profile (SIP) was selected to be administered as a measure of the subject’s self-report on
level of adaptive functioning omitting items SI9, SI17, and SI19 (see Appendix 1). The outcome measure was the SIP Psychosocial score (Bergner et al., 1976).

The SIP is composed of 136 items (questions answered in a yes-no format), grouped into 12 categories which evaluates a wide range of quality of life domains that include sleep and rest, emotional behaviour, body care and movement, home management, mobility, social interaction, ambulation, alertness behaviour, communication, recreation and pastimes, eating, and work. Scores on this measure are expressed in terms of percentage of dysfunction for each of the subscales and a total dysfunction score and is sensitive enough to detect changes across time in health status among groups of subjects at both low and high levels of dysfunction.

Within the 12 categories, 7 are aggregated into 2 dimensions, physical and psychosocial and each item is weighted on a scale of 1-11 with higher weights signifying greater dysfunction. Item scores (weights) represent social preference weights from the perspective of health care providers from multiple disciplines and have been statistically and clinically validated. Aggregate scores (range 0-100) computed at the category, subscale, and total instrument levels are all proportions. Total weights for each category and subscale were not empirically determined and do not represent social preference weights.

Each participant requesting a mailed questionnaire was
also provided with a written description of the study, a Consent Form and a Physician Information copy (see Appendix 2, 3, & 4).

As reported in the Knights et al (1991) study, the socioeconomic level of the individual in the current study was determined by the original rank ordering on the Blishen and McRoberts (1976) economic index (range 1-480) which is based on a revised socioeconomic index for occupations in Canada. The average SES level of the group was at the economic index level of 45.8 for the mild group, 43.7 for the moderate group, and 41.8 for the severe group.

PROCEDURE:

Attempts were made to contact the participants by telephone using the phone numbers obtained from the general information forms initially completed by the child's parents. In a few cases, the family still maintained the same phone number and provided the address and phone number where the participant now resided. In many cases, however, the family no longer maintained the phone number and were not listed in the Ottawa area phonebook. In order to maximize the number of participants, a list was compiled using the CD Rom Canada Phonebook of those registered having the same name or initials as the participant or family member noted on the original information form. Calls were placed to all those listed. However, in the majority of
cases the participants could not be located. Attempts were also made to locate participants through hospital admissions records, but to no avail.

When the participants were located and initial telephone contact was made, each individual participant was advised of the follow-up study and given a short description of the study. They were then asked if they would be willing to participate in the study. If they chose to participate, they were asked to cooperate in the completion of a questionnaire regarding their current psychosocial status.

The participants were informed that the questionnaire was to be administered over the telephone and would take approximately 20 minutes. If a participant was willing, the interviewer administered the SIP questionnaire immediately or arranged a more convenient time. Instructions to the respondent were as follows:

"Before beginning the questionnaire, I am going to read you the instructions. You have certain activities that you do in carrying on your life. Sometimes you do all of these activities. Other times, because of your state of health, you don’t do these activities in the usual way: you may cut some out; you may do some for shorter lengths of time; you may do some in different ways. These changes in your activities might be recent or longstanding. We are interested in learning about any changes that describe you today and are related to
your state of health.
I will be reading statements that people have told us describe them when they are not completely well. Whether or not you consider yourself sick, there may be some statements that stand out because they describe you today and are related to your state of health. As I read the questionnaire, think of yourself today. I will pause briefly after each statement. When you hear one that does describe you and is related to health please tell me and I will check it. Let me give you an example. I might read the statement "I am not driving my car." If this statement is related to your health and describes you today, you should tell me. Also, if you have not been driving for some time because of your health, and are still not driving today, you should respond to this statement. On the other hand, if you never drive or are not driving today because your car is being repaired, the statement, "I am not driving my car" is not related to your health and you should not respond to it. If you simply are driving less, or are driving shorter distances, and feel that the statement only partially describes you, please do not respond to it. I am now going to begin the questionnaire. Please tell me if you want me to slow down, repeat a statement, or stop so that you can think about one. Also let me know
any time you would like to review the instructions. Remember we are interested in the recent or longstanding changes in your activities that are related to your health."

In many cases (n=25), participants requested that the questionnaire be mailed to them. In these cases, the SIP questionnaire, description form, consent form, and physician information form was promptly mailed along with a stamped, self-addressed return envelope.

Although other aspects of psychosocial adjustment (education level, nature of work, and experience of seizures) were investigated during the interviews, only the data pertaining to the SIP are presented in this study. All participants were voluntary, and none of the participants interviewed gained benefit from this study.

RESULTS:

Of the 76 individuals in the original sample, two were deceased and only 36 could be contacted. Of the 36, four individuals refused to participate and seven questionnaires were not returned despite a follow-up phone call, a written reminder, and a second SIP questionnaire mailed to them.

Demographic information with respect to the original sample, the present sample, and the non-participants is shown in Table 3.

Of those who participated in this study, nine (33%)
responded by telephone interview and 18 (66%) responded by mail.

The mean age at time of follow-up was 22 years (SD=3.2 years; range: 16-28 years). The number participating from each severity of injury group was: mild 16; moderate 9; severe 5. The demographic and clinical details of the participants are summarized in Table 4.

The SIP questionnaire was scored as recommended in the SIP manual (Department of Health Services, 1977). Table 5 presents the percentage dysfunction in various activities of daily life as reported by participants on the SIP Psychosocial subscale.

A hierarchical regression analysis was performed on SIP psychosocial subscale to evaluate the effect of severity of injury on the SIP score. Socioeconomic status was forced into the function as the first predictor to determine whether other variables could improve this discrimination significantly. Age at injury was entered as the second predictor, after which the contribution of severity of injury was entered. The regression analysis performed on the SIP psychosocial data revealed no significant effect for SES, age at injury, or severity of injury. A summary of the results is shown in Table 6.
Table 3. Comparison of Demographics for Original, Present, and Non-participant samples.

<table>
<thead>
<tr>
<th></th>
<th>ORIGINAL GROUP</th>
<th>PRESENT GROUP</th>
<th>NON-RESPONDENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AGE</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 -17 years</td>
<td>50/26</td>
<td>21/6</td>
<td>4/3</td>
</tr>
<tr>
<td>16-28 years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-25 years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>MALE/FEMALE</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(mild)</td>
<td>42%</td>
<td>59%</td>
<td>28%</td>
</tr>
<tr>
<td>(moderate)</td>
<td>23%</td>
<td>22%</td>
<td>42%</td>
</tr>
<tr>
<td>(severe)</td>
<td>34%</td>
<td>18%</td>
<td>28%</td>
</tr>
</tbody>
</table>

**SEVERITY**

**AVERAGE SOCIOECONOMIC STATUS**

<table>
<thead>
<tr>
<th></th>
<th>ORIGINAL GROUP</th>
<th>PRESENT GROUP</th>
<th>NON-RESPONDENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>(mild)</td>
<td>45.8</td>
<td>46.2</td>
<td>42.2</td>
</tr>
<tr>
<td>(moderate)</td>
<td>43.7</td>
<td>43.7</td>
<td>37.7</td>
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<tr>
<td>(severe)</td>
<td>41.8</td>
<td>29.4</td>
<td>40.9</td>
</tr>
</tbody>
</table>

* Measured by the Glasgow Coma Scale

** Measured by the Blishen Index
Table 4. Demographic and clinical details of participants.

<table>
<thead>
<tr>
<th>Participant No.</th>
<th>Age at Injury</th>
<th>Present Age</th>
<th>Severity of Injury*</th>
<th>Socio-economic index+</th>
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<tbody>
<tr>
<td>1</td>
<td>8.4</td>
<td>19</td>
<td>severe</td>
<td>29.4705</td>
</tr>
<tr>
<td>2</td>
<td>9.0</td>
<td>23</td>
<td>severe</td>
<td>28.8448</td>
</tr>
<tr>
<td>3</td>
<td>13.9</td>
<td>25</td>
<td>severe</td>
<td>37.6162</td>
</tr>
<tr>
<td>4</td>
<td>13.7</td>
<td>25</td>
<td>mild</td>
<td>43.1314</td>
</tr>
<tr>
<td>5</td>
<td>7.5</td>
<td>18</td>
<td>mild</td>
<td>32.2318</td>
</tr>
<tr>
<td>6</td>
<td>9.9</td>
<td>24</td>
<td>mild</td>
<td>37.6721</td>
</tr>
<tr>
<td>7</td>
<td>10.0</td>
<td>23</td>
<td>moderate</td>
<td>72.2955</td>
</tr>
<tr>
<td>8</td>
<td>15.0</td>
<td>27</td>
<td>moderate</td>
<td>72.2955</td>
</tr>
<tr>
<td>9</td>
<td>7.0</td>
<td>18</td>
<td>mild</td>
<td>55.5801</td>
</tr>
<tr>
<td>10</td>
<td>8.9</td>
<td>20</td>
<td>moderate</td>
<td>28.7070</td>
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<tr>
<td>11</td>
<td>5.0</td>
<td>16</td>
<td>mild</td>
<td>28.6236</td>
</tr>
<tr>
<td>12</td>
<td>12.0</td>
<td>27</td>
<td>mild</td>
<td>68.7215</td>
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<tr>
<td>13</td>
<td>8.9</td>
<td>23</td>
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<td>52.2331</td>
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<tr>
<td>14</td>
<td>13.9</td>
<td>25</td>
<td>mild</td>
<td>74.2246</td>
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<tr>
<td>15</td>
<td>8.0</td>
<td>23</td>
<td>mild</td>
<td>72.7302</td>
</tr>
<tr>
<td>16</td>
<td>15.0</td>
<td>28</td>
<td>mild</td>
<td>46.2227</td>
</tr>
<tr>
<td>17</td>
<td>16.3</td>
<td>27</td>
<td>mild</td>
<td>72.2955</td>
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<tr>
<td>18</td>
<td>12.0</td>
<td>26</td>
<td>moderate</td>
<td>37.6721</td>
</tr>
<tr>
<td>19</td>
<td>12.0</td>
<td>25</td>
<td>mild</td>
<td>23.0227</td>
</tr>
<tr>
<td>20</td>
<td>9.0</td>
<td>24</td>
<td>moderate</td>
<td>43.7909</td>
</tr>
</tbody>
</table>

(continued)
### Table 4 (continued)

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
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</thead>
<tbody>
<tr>
<td>21</td>
<td>7.0</td>
<td>20</td>
<td>mild</td>
<td>54.2791</td>
</tr>
<tr>
<td>22</td>
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<td>severe</td>
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<td>23</td>
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<td>24</td>
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<td>25</td>
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<td>20</td>
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<td>26</td>
<td>11.4</td>
<td>24</td>
<td>severe</td>
<td>43.7909</td>
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<tr>
<td>27</td>
<td>13.4</td>
<td>22</td>
<td>mild</td>
<td>35.3916</td>
</tr>
</tbody>
</table>

*as measured by the GCS

+as measured by Blishen’s 1971 scale
Table 5. Percentage of dysfunction on the SIP

<table>
<thead>
<tr>
<th>Participant</th>
<th>Psychosocial Score</th>
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<tr>
<td>1</td>
<td>4.36</td>
</tr>
<tr>
<td>2</td>
<td>2.25</td>
</tr>
<tr>
<td>3</td>
<td>19.55</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>6</td>
<td>22.18</td>
</tr>
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<td>7</td>
<td>0</td>
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<tr>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>9</td>
<td>12.71</td>
</tr>
<tr>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>11</td>
<td>15.45</td>
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<td>16</td>
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<td>18</td>
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(continued)
Table 5 (continued)

<p>| | |</p>
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<tr>
<td>Mean</td>
<td>5.12</td>
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<td>Mode</td>
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Table 6. Summary of Hierarchical regression Analysis for Variables Predicting Psychosocial Adjustment (N=27)

<table>
<thead>
<tr>
<th>Variable</th>
<th>$\Delta \hat{r}^2$</th>
<th>$r'$</th>
<th>$F$</th>
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</thead>
<tbody>
<tr>
<td>Socioeconomic status</td>
<td>.00048</td>
<td>.00049</td>
<td>.01229</td>
</tr>
<tr>
<td>Age at injury</td>
<td>.03831</td>
<td>.03872</td>
<td>.48329</td>
</tr>
<tr>
<td>Severity of injury</td>
<td>.00777</td>
<td>.04656</td>
<td>.37442</td>
</tr>
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</table>

*Note.* (ps > .05)

(continued)
Table 6 (continued)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>Beta</th>
</tr>
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<tbody>
<tr>
<td>Socioeconomic status</td>
<td>-8.3777</td>
<td>.094703</td>
<td>-.002046</td>
</tr>
<tr>
<td>Age at injury</td>
<td>-.4899</td>
<td>.526160</td>
<td>-.198233</td>
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<tr>
<td>Severity of injury</td>
<td>-.8771</td>
<td>2.015705</td>
<td>-.096427</td>
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Note. (ps > .05)

**DISCUSSION:**

The primary goal of this study was to document the
DISCUSSION:

The primary goal of this study was to document the psychosocial status of young adults who experienced either a mild, moderate, or severe CHI during childhood. A second goal was to see if various factors, such as SES, age at time of injury, and severity of injury are reliable predictors of psychosocial adjustment, specifically with respect to young adults who sustained a head injury during childhood.

It was not anticipated that the results of this study would differ from those reported in previous investigations (Asarnow et al., 1991; Brooks, 1992; Hendryx, 1989; Klonoff et al., 1986; Lezak, 1987, 1995; Morton & Wehman, 1995; Oddy et al., 1978; Prigatano, 1987; Varney & Menefee, 1993). However, the present study does not provide evidence that psychosocial problems are a consequence of head injury. No statistically significant findings were in evidence with respect to SES, age at injury, and severity of injury predicting psychosocial adjustment in adult life.

The hypothesis was that SES, age at injury, and severity of injury would predict levels of psychosocial dysfunction. This hypothesis was not confirmed. A possible reason for lack of prediction lies in the nature of the dependent variable. SIP psychosocial subscale scores may be seen as a measure of the relative psychosocial dysfunction of the individual participants. Within the study population there was very low variance on the SIP and therefore,
statistically, prediction was not possible.

The results of this study could lead to two possibly erroneous conclusions. First, it may be concluded that SIP measures are not sensitive to the effects of traumatic head injury, and second, that adults who sustained a head injury during childhood, as a group, do not show long-term psychosocial adjustment problems at 10 years.

Interpretations of the results should be made in light of limitations of the sample, design, and measures. The targeted sample was individuals who had suffered traumatic head injury during childhood and had participated in Knight's et al. (1991) study. It was not known whether or not the individuals who participated in the study are those who have made a successful recovery as opposed to those with persisting problems. Another limitation of the sample was that it was not known if those who chose not to participate had preferential involvement of frontal or temporal lobes. Because the frontal and temporal lobes are more vulnerable in CHI than are other brain structures, deficits typical for CHI could result from frontal or temporal lesions. Typically, these patients are impulsive, have poor social judgment, misperceive the intentions or actions of others, are slower in processing information, and complain of memory disturbance (Prigatano & Fordyce, 1986). If those individuals who could not be located or who refused to respond differed from the rest of the participants, this
The data collected were all based on self-reports. SIP assessment information is subjective and represents the perception of the impact of the injury on the individual. A strength of the design was its measurement of change in psychosocial functioning. The SIP was chosen as the criterion measure for this study because previous work showed it to be responsive to change and is one of the most commonly employed self-report measures of functional status (Brooks, Jordan, Divine, Smith, & Neelon, 1990; Katz, Larson, Phillips, Fossel, & Liang, 1992). The SIP provides a descriptive profile of the effects of ill health on behaviour and is an efficient instrument for identifying changes in an individual's psychosocial functioning. It captures a range of function extending to the very lower levels, and has been used and validated in many demographic subgroups, types and severities of illness (Bergner et al., 1976). It should be noted that the SIP psychosocial score for an individual is based on his or her responses to the SIP items. This assumes that the individual is providing a valid and truthful account of the subjective level of psychosocial functioning. In the present study, SIP Psychosocial subscale scores cluster in the extreme lower end of the 100-point scale, which could indicate that many items on the SIP may not be germane to this population.

On a practical level, however, the SIP scales have been tested on adult populations. There is a lack of scales
designed specifically for children and adolescents. Future research in this area should include development or revision of scales assessing change in psychosocial functioning for use with children and adolescents. Further, results would be strengthened if data were collected at various stages of recovery over a long period of time. Such longitudinal studies would permit the examination of developmental change in psychosocial functioning.

The study perhaps would be strengthened by also collecting corroborating information from family members. It may be particularly useful if the same questions were to be asked of the participant and of family members in subsequent follow-up studies of children and adolescents.

Because of the retrospective nature of this investigation, premorbid information about the participants was incomplete. Therefore, a prospective research design is recommended which may alleviate the problems associated with retrospective studies. In this way, it would allow for a better insight into the psychosocial recovery after CHI in children and the predictive values of selected variables.

Previous studies have indicated that SES appears to be an important predictor of adjustment, coping skills, and patient outcome in adult studies (Adler et al., 1994; Feinstein, 1993; McLeod & Kessler, 1990; Rutter, 1981; Waaland et al., 1993). Given this, future research should include a broad range of adjunctive measures documented from
more than one source to gain a more overall picture of the individual. For example, premorbid functioning levels (previous head injury), premorbid personality traits (including the nature of relationships with others), the child's behavioral characteristics prior to injury, health behaviours (smoking, alcohol, physical activity), psychological factors (depression, stress, coping style with respect to stressful events), level of preinjury work or school adjustment, family dynamics, and access to health care.

Numerous investigations suggest that the age of the individual at the time of the injury has an important bearing on eventual functional outcome. In general, the younger patient, the better the recovery of function (Braakman et al., 1980; Levin, 1992; Knights et al., 1991). Several other studies, however, have reported that age at the time of injury was not related to rate of recovery (Berger et al., 1985; Levin & Eisenberg, 1979). In the present study, the overall psychosocial adjustment of the participants does not appear to have been affected by the child's age at the time of the brain injury.

Evidence about the relation of the age at injury to outcome is contradictory and the inability to demonstrate a relationship between age at injury and psychosocial adjustment does not rule out the possibility that this factor may prove to be associated with psychosocial
adjustment.

The plasticity of the developing brain often allows for dramatic recovery of function (Chadwick et al., 1981). Age may be associated with psychological capabilities in tolerating head injury as well as her/his ability to compensate for or adapt to subsequent impairments. However, besides age and age-related brain plasticity other factors such as premorbid personality, past experience, and acquired behavioral repertoires will differ between children. Also, the nature of the brain pathology may be different, affecting psychosocial outcome. It should also be emphasized that intervening life events between the initial project and the current study would have an interactive effect on long-term psychosocial adjustment.

Contrary to the initial hypothesis and to previous studies (eg., Dikmen & Machamer, 1995), severity of injury did not predict psychosocial adjustment. The negative finding may be a consequence in part of the relationship between severity and site of injury that operates to either exacerbate or mitigate the impact of the severity index. Although the severity of head injury is related to neuropsychological impairments, including the faculties of language, memory, and visuospatial and visuomotor abilities as indicated by test scores (Bawden, Knights, & Winogron, 1985; Knights et al, 1991), these deficits only partly determine psychosocial outcome. Factors such as site of
injury are reported as confounding the relationship between brain pathology and psychosocial sequelae (Lezak, 1978, 1987; Vilkki et al, 1993). The decision to base the main index of severity of injury on the recorded GCS was because it was the only available index in the medical record. Further, in most of the literature it is now conventionally accepted that the GCS is a prime indicator for assessment of depth and duration of coma and most researchers attempting to relate severity of injury to outcome use the GCS as a primary measure.

Prediction of psychosocial outcome relates to the patient's capacity to reintegrate socially and function independently. Previous studies have shown that the depth of coma is a valid predictor of outcome in large heterogeneous groups of head injured patients (Rowley & Fielding, 1991;). In contrast, in a recent investigation of factors predicting return to work or school, Ip, Dornan & Schentag (1995) report that brain injury severity as measured by GCS did not reliably predict vocational/educational outcome and the authors suggest depth of coma might be a less reliable predictor of outcome.

It has been argued that the GCS, based on gross measures of neurological deficit is unlikely to be sensitive to subtle psychosocial impairment. For example, Giacino and Zasler (1995) state the GCS consists largely of items that tend to lose their predictive utility subsequent to the
acute period and are relatively insensitive to subtle changes in neurological responsiveness over time. The authors note that severity indices are most useful during the first two weeks after injury when they are capable of predicting functional outcome. However, they are generally not highly predictive of late (>6 months) functional outcome.

Dikmen and Machamer (1995) found depth of coma to be closely and systematically related to neuropsychological functioning soon after injury, with this relationship becoming a little weaker later. The authors state that although duration of coma may be a useful predictor of outcome following head injury in adults, its prognostic usefulness after children's head injuries is less certain largely because of the use of different coma definition systems. Given the current knowledge of brain/behaviour relationships, the use of GCS on its own may not be a good measure to use or a reliable predictor of long-term psychosocial adjustment. More confident predictions can be made when predictors are based in a combination of prognostic indicators due to the inherent interactions between predictors. For example, between the GCS and CT findings.

Further studies are needed to investigate the accuracy and quality of prediction of the level of psychosocial adjustment and long-term outcome from CHI during childhood.
and adolescence. Longitudinal studies charting developmental change would provide insights into the processes surrounding psychosocial functioning during recovery from childhood head injury. Future research could use an adapted version of the SIP scales to examine children and adolescents' psychosocial functioning. Consequent follow-up functional assessments of children (or at least testing after a scheduled period of time) is essential to the evaluation of long range implications of findings during the stages of recovery.
References


APPENDIX A

SIP QUESTIONNAIRE
LONG-TERM PSYCHOSOCIAL ADJUSTMENT
FOLLOWING A
HEAD INJURY

PLEASE READ THE ENTIRE INSTRUCTIONS BEFORE YOU READ THE QUESTIONNAIRE. IT IS VERY IMPORTANT THAT EVERYONE TAKING THE QUESTIONNAIRE FOLLOWS THE SAME INSTRUCTIONS.

Introduction

Great effort is currently being put forward to improve our understanding of the long-term effects of a head injury. Information on the type of impact that a head injury has on an individual's life would help us better understand the mechanisms of such trauma and consequently, would ameliorate our management. In order to obtain such information, we need you to fill out the following questionnaire.

Instructions

You have certain activities that you do in carrying on your life. Sometimes you do all of these activities. Other times, because of your state of health, you don't do these activities in the usual way: you may cut some out; you may do some for shorter lengths of time; you may do some in different ways. These changes in your activities might be recent or longstanding. We are interested in learning about any changes that describe you today and are related to your state of health.

The questionnaire lists statements that people have told us describe them when they are not completely well. Whether or not you consider yourself sick, there may be some statements that will stand out because they describe you today and are related to your state of health. As you read the questionnaire, think of yourself today. When you read a statement that you are sure describes you and is related to your health, place a check on the line to the right of the statement. For example:

I am not driving my car

If you have not been driving for some time because of your health, and are still not driving today, you should respond to this statement.

On the other hand, if you never drive or are not driving today because your car is being repaired, the statement, "I am not driving" is not related to your health and you should not check it. If you simply are driving
less, or are driving shorter distances, and feel that the
statement only partially describes you, do not check it. In
all these cases you would leave the line to the right of the
statement blank. For example:

I am not driving my car

Remember that we want you to check this statement only
if you are sure it describes you today and is related to
your state of health.

Read the introduction to each group of statements and
then consider the statements in the order listed. While
some of the statements may not apply to you, we ask that you
please read all of them. Check those that describe you as
you go along. Some of the statements will differ only in a
few words, so please read each one carefully. While you may
go back and change a response, your first answer is usually
the best. Please do not read ahead.

Once you have started the questionnaire, it is very
important that you complete it within one day (24 hours).

If you find it hard to keep your mind on the
statements, take a short break and then continue. When you
have read all the statements on a page, put a check in the
BOX in the lower right-hand corner. If you have any
questions, please refer back to these instructions.

Please do not discuss the statements with anyone,
including family members, while doing the questionnaire.

Now turn to the questionnaire and read the statements.
Remember we are interested in the recent or longstanding
changes in your activities that are related to your head
injury.
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I spend much of the day lying down in order to rest ______ (070-083)

2. I sit during much of the day ______ (062-049)

3. I am sleeping or dozing most of the time - day and night ______ (063-104)

4. I lie down more often during the day in order to rest ______ (065-058)

5. I sit around half-asleep ______ (065-084)

6. I sleep less at night, for example, wake up too early, don't fall asleep for a long time, awaken frequently ______ (069-061)

7. I sleep or nap more during the day ______ (071-060)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE [ ]
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I say how bad or useless I am, for example, that I am a burden on others   (274-087)

2. I laugh or cry suddenly   (272-068)

3. I often moan and groan in pain or discomfort   (269-069)

4. I have attempted suicide   (281-132)

5. I act nervous or restless   (284-046)

6. I keep rubbing or holding areas of my body that hurt or are uncomfortable   (262-062)

7. I act irritable and impatient with myself, for example, talk badly about myself, swear at myself, blame myself for things that happen   (273-078)

8. I talk about the future in a hopeless way   (283-089)

9. I get sudden frights   (278-074)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE   □
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE
DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I make difficult moves with help, for example, getting into or out of cars, bathtubs</td>
<td>(168-084)</td>
</tr>
<tr>
<td>2</td>
<td>I do not move into or out of bed or chair by myself but am moved by a person or mechanical aid</td>
<td>(170-121)</td>
</tr>
<tr>
<td>3</td>
<td>I stand only for short periods of time</td>
<td>(155-072)</td>
</tr>
<tr>
<td>4</td>
<td>I do not maintain balance</td>
<td>(146-090)</td>
</tr>
<tr>
<td>5</td>
<td>I move my hands or fingers with some limitation or difficulty</td>
<td>(152-064)</td>
</tr>
<tr>
<td>6</td>
<td>I stand up only with someone's help</td>
<td>(165-100)</td>
</tr>
<tr>
<td>7</td>
<td>I kneel, stoop, or bend down only by holding on to something</td>
<td>(171-064)</td>
</tr>
<tr>
<td>8</td>
<td>I am in a restricted position all the time</td>
<td>(158-125)</td>
</tr>
<tr>
<td>9</td>
<td>I am very clumsy in body movements</td>
<td>(148-058)</td>
</tr>
<tr>
<td>10</td>
<td>I get in and out of bed or chairs by grasping something for support or using a cane or walker</td>
<td>(169-082)</td>
</tr>
<tr>
<td>11</td>
<td>I stay lying down most of the time</td>
<td>(162-113)</td>
</tr>
<tr>
<td>12</td>
<td>I change position frequently</td>
<td>(147-030)</td>
</tr>
<tr>
<td>13</td>
<td>I hold on to something to move myself around in bed</td>
<td>(143-086)</td>
</tr>
<tr>
<td>14</td>
<td>I do not bathe myself completely, for example, require assistance with bathing</td>
<td>(310-089)</td>
</tr>
<tr>
<td>15</td>
<td>I do not bathe myself at all, but am bathed by someone else</td>
<td>(312-115)</td>
</tr>
<tr>
<td>16</td>
<td>I use bedpan with assistance</td>
<td>(292-114)</td>
</tr>
<tr>
<td>17</td>
<td>I have trouble getting shoes, socks, or stockings on</td>
<td>(305-057)</td>
</tr>
<tr>
<td>18</td>
<td>I do not have control of my bladder</td>
<td>(290-124)</td>
</tr>
</tbody>
</table>
(CONTINUED FROM PAGE 7)

19. I do not fasten my clothing, for example, require assistance with buttons, zippers, shoelaces ___________ (290-074)

20. I spend most of the time partly undressed or in pajamas ___________ (302-074)

21. I do not have control of my bowels ___________ (295-128)

22. I dress myself, but do so very slowly ___________ (300-043)

23. I get dressed only with someone's help ___________ (297-088)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE □
THIS GROUP OF STATEMENTS HAS TO DO WITH ANY WORK YOU USUALLY DO IN CARING FOR YOUR HOME OR YARD. CONSIDERING JUST THOSE THINGS THAT YOU DO, PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH

1. I do work around the house only for short periods of time or rest often

2. I am doing less of the regular daily work around the house than I would usually do

3. I am not doing any of the regular daily work around the house that I would usually do

4. I am not doing any of the maintenance or repair work that I would usually do in my home or yard

5. I am not doing any of the shopping that I would usually do

6. I am not doing any of the house cleaning that I would usually do

7. I have difficulty doing handwork, for example, turning faucets, using kitchen gadgets, sewing, carpentry

8. I am not doing any of the clothes washing that I would usually do

9. I am not doing heavy work around the house

10. I have given up taking care of personal or household business affairs, for example, paying bills, banking, working on budget

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE □
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE
DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I am getting around only within one building  ____ (134-086)
2. I stay within one room  ____ (128-166)
3. I am staying in bed more  ____ (130-001)
4. I am staying in bed most of the time  ____ (131-109)
5. I am not now using public transportation  ____ (140-041)
6. I stay home most of the time  ____ (133-066)
7. I am only going to places with restrooms nearby  ____ (125-056)
8. I am not going into town  ____ (124-048)
9. I stay away from home only for brief periods of time  ____ (139-054)
10. I do not get around in the dark or in unlit places
    without someone's help  ____ (121-072)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE □
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I am going out less to visit people
   (028-044)
2. I am not going out to visit people at all
   (029-101)
3. I show less interest in other people's problems, for example, don't listen when they tell me about their problems, don't offer to help
   (003-067)
4. I often act irritable toward those around me, for example, snap at people, give sharp answers, criticize easily
   (015-084)
5. I show less affection
   (007-052)
6. I am doing fewer social activities with groups of people
   (012-036)
7. I am cutting down the length of visits with friends
   (027-043)
8. I am avoiding social visits from others
   (034-080)
9. My sexual activity is decreased
   (039-051)
10. I often express concern over what might be happening to my health
    (018-052)
11. I talk less with those around me
    (002-056)
12. I make many demands, for example, insist that people do things for me, tell them how to do things
    (038-088)
13. I stay alone much of the time
    (023-086)
14. I act disagreeable to family members, for example, I act spiteful, I am stubborn
    (249-088)
15. I have frequent outbursts of anger at family members, for example, strike at them, scream, throw things at them
    (240-119)
16. I isolate myself as much as I can from the rest of the family
    (237-102)
17. I am paying less attention to the children          \( (238-064) \)

18. I refuse contact with family members, for example, turn away from them        \( (256-115) \)

19. I am not doing the things I usually do to take care of my children or family         \( (242-079) \)

20. I am not joking with family members as I usually do            \( (255-043) \)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE □
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE
DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I walk shorter distances or stop to rest often           (050-048)
2. I do not walk up or down hills                          (046-056)
3. I use stairs only with mechanical support, for example, handrail, cane, crutches (042-067)
4. I walk up or down stairs only with assistance from someone else (044-076)
5. I get around in a wheelchair                            (057-096)
6. I do not walk at all                                     (052-105)
7. I walk by myself but with some difficulty, for example, limp, wobble, stumble, have stiff leg (049-055)
8. I walk only with help from someone                       (053-088)
9. I go up and down stairs more slowly, for example, one step at a time, stop often (040-054)
10. I do not use stairs at all                              (041-083)
11. I get around only by using a walker, crutches, cane, walls, or furniture (047-079)
12. I walk more slowly                                      (051-035)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE
DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I am confused and start several actions at a time (223-090)

2. I have more minor accidents, for example, drop things, trip and fall, bump into things (234-075)

3. I react slowly to things that are said or done (228-059)

4. I do not finish things I start (227-067)

5. I have difficulty reasoning and solving problems, for example, making plans, making decisions, learning new things (224-084)

6. I sometimes behave as if I were confused or disoriented in place or time, for example, where I am, who is around, directions, what day it is (231-113)

7. I forget a lot, for example, things that happened recently, where I put things, appointments (222-078)

8. I do not keep my attention on any activity for long (220-067)

9. I make more mistakes than usual (225-064)

10. I have difficulty doing activities involving concentration and thinking (217-080)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE
DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I am having trouble writing or typing (191-070)

2. I communicate mostly by gestures, for example,
   moving head, pointing, sign language (177-102)

3. My speech is understood only by a few people
   who know me well (179-093)

4. I often lose control of my voice when I talk,
   for example, my voice gets louder or softer,
   trembles, changes unexpectedly (197-083)

5. I don't write except to sign my name (188-083)

6. I carry on a conversation only when very close
   to the other person or looking at him (178-067)

7. I have difficulty speaking, for example, get
   stuck, stutter, stammer, slur my words (176-076)

8. I am understood with difficulty (200-087)

9. I do not speak clearly when I am under stress (201-064)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE □
The next group of statements has to do with any work you usually do other than managing your home. By this we mean anything that you regard as work that you do on a regular basis.

Do you usually do work other than managing your home?

→ YES  NO

→ If you answered yes, go on to the next page.

→ If you answered no:

Are you retired?

→ YES  NO

If you are retired, was your retirement related to your health?

→ YES  NO

If you are not retired, but are not working, is this related to your health?

→ YES  NO

→ Now skip the next page.
IF YOU ARE NOT WORKING AND IT IS NOT BECAUSE OF YOUR HEALTH, PLEASE SKIP THIS PAGE.

NOW CONSIDER THE WORK YOU DO AND RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH. (IF TODAY IS A SATURDAY OR SUNDAY OR SOME OTHER DAY THAT YOU WOULD USUALLY HAVE OFF, PLEASE RESPOND AS IF TODAY WERE A WORKING DAY.)

1. I am not working at all
   (IF YOU CHECKED THIS STATEMENT, SKIP TO THE NEXT PAGE.)
   ____ (100-361)

2. I am doing part of my job at home
   ____ (094-037)

3. I am not accomplishing as much as usual at work
   ____ (096-055)

4. I often act irritable toward my work associates, for example, snap at them, give sharp answers, criticize easily
   ____ (088-080)

5. I am working shorter hours
   ____ (095-043)

6. I am doing only light work
   ____ (096-050)

7. I work only for short periods of time or take frequent rescs
   ____ (090-061)

8. I am working at my usual job but with some changes, for example, using different tools or special aids, trading some tasks with other workers
   ____ (092-034)

9. I do not do my job as carefully and accurately as usual
   ____ (097-062)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE □
THIS GROUP OF STATEMENTS HAS TO DO WITH ACTIVITIES YOU USUALLY DO IN YOUR FREE TIME. THESE ACTIVITIES ARE THINGS THAT YOU MIGHT DO FOR RELAXATION, TO PASS THE TIME, OR FOR ENTERTAINMENT. PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I do my hobbies and recreation for shorter periods of time ______ (215-039)

2. I am going out for entertainment less often ______ (214-036)

3. I am cutting down on some of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading ______ (207-059)

4. I am not doing any of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading ______ (208-084)

5. I am doing more inactive pastimes in place of my other usual activities ______ (211-051)

6. I am doing fewer community activities ______ (216-033)

7. I am cutting down on some of my usual physical recreation or activities ______ (210-043)

8. I am not doing any of my usual physical recreation or activities ______ (209-077)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE □
PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

1. I am eating much less than usual

2. I feed myself but only by using specially prepared food or utensils

3. I am eating special or different food, for example, soft food, bland diet, low-salt, low-fat, low-sugar

4. I eat no food at all but am taking fluids

5. I just pick or nibble at my food

6. I am drinking less fluids

7. I feed myself with help from someone else

8. I do not feed myself at all, but must be fed

9. I am eating no food at all, nutrition is taken through tubes or intravenous fluids

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐
NOW, PLEASE REVIEW THE QUESTIONNAIRE TO BE CERTAIN YOU HAVE FILLED OUT ALL THE INFORMATION. LOOK OVER THE BOXES ON EACH PAGE TO MAKE SURE EACH ONE IS CHECKED SHOWING THAT YOU HAVE READ ALL OF THE STATEMENTS. IF YOU FIND A BOX WITHOUT A CHECK, THEN READ THE STATEMENTS ON THAT PAGE.
APPENDIX B

WRITTEN DESCRIPTION
A 10 YEAR FOLLOW-UP STUDY OF CHILDREN WITH HEAD INJURIES: PSYCHOSOCIAL AND VOCATIONAL ADJUSTMENT

STUDY DESCRIPTION AND CONSENT FORM

Approximately 10 years ago, between 1981 and 1986, you participated in a study of children suffering head trauma conducted by Dr. Robert M. Knights and Dr. Enrique Ventureyra. Your parents or guardians were interviewed and you were assessed on three occasions by Carol Bentivoglio. In general, at the last assessment, the results showed a very good recovery from head trauma. The group data have been published and are available to you if requested.

We would now like to do a follow-up study to find out what you have done in the intervening 10 years and what you are doing now. Our plan is to ask you to cooperate in completing a questionnaire which asks questions about various aspects of your life. This questionnaire will ask you questions about any physical symptoms you have, your educational progress, some of your personality characteristics, where you are living, and, if you work, the nature of your employment.

As soon as you were contacted by telephone we sent you the attached Consent Form and hope you will agree to participate by completing the follow-up questionnaire.

Any questions regarding ethical guidelines should be addressed to either Dr. L. Pacquet (ethics committee) or Dr. B. Jones, Chairman, Department of Psychology, Carleton University - phone 788-2644.

We look forward to discussing the project with you. If you have any questions, please call or Fax me at the numbers indicated below.

Thank you,

Robert M. Knights, Ph.D., C.Psych.
Phone: (613) 788-2673
Fax: (613) 730-8525

or

Lynn Gervais, H.B.A.
Phone: (613) 788-2673
Carol Bentivoglio, B.A.
Phone: CHEO: 737-2492
APPENDIX C

CONSENT FORM
CONSENT FORM

Dr. Robert M. Knights, Lynn Gervais and Carol Bentivoglio

Psychology Department
Children’s Hospital of Eastern Ontario
401 Smyth Road, Ottawa, Ontario, K1H 8L1

1. I understand this is a follow-up study that will ask questions about various aspects of my life. I also acknowledge that this study is important in helping to understand the long-term effects of head injury.

2. This information is confidential and is protected under the Freedom of Information and Protection of Privacy Act, 1989 (Bill 49).

3. I acknowledge that the research procedures have been explained to me, and that any questions that I have asked have been answered to my satisfaction. In addition, I know that I may contact Dr. Knights if I have further questions either now or in the future.

4. I have been assured that personal records relating to this study will be kept confidential. I understand that I am free to withdraw from the study at any time.

5. I have read and understood the request for me to participate in the study described on the attached page. I have decided to

[ ] participate in the study
[ ] not participate in the study

Name: ____________________________________________

Signature of subject: ________________________________

Signature of parent/guardian: ________________________

Signature of Witness: ______________________________

Date: ____________________________________________

Please return this sheet as soon as possible.

Thank you very much for your cooperation.

Dr. R.M. Knights
Phone: (613) 788-2673 Fax: (613) 730-8525

Lynn Gervais – Phone: 788-2673
APPENDIX D

PHYSICIAN COPY
To: Dr. X:

We are about to conduct a 10 year follow-up study of head injured children who were hospitalized at CHEO between 1981 - 1986. The person listed below has indicated you are her/his primary physician at the present time. In order to inform you of the nature of this study I have included a copy of the Study Description and the signed Consent Form, as well as a description of the Design and Methodology.

If you have any concerns regarding the participation of your patient in this study, please contact me at the numbers listed below.

Thank you for your cooperation.

Sincerely,

Robert M. Knights, PhD., C.Psych.
Phone: 788-2673
Fax: 730-8525

Name of patient:__________________________________________________________

Date of birth: __________________________________________________________

Copies: Study Description
Consent Form
Design Form
PM-1 3½"x4" PHOTOGRAPHIC MICROCOPY TARGET
NBS 1010a ANSI/ISO #2 EQUIVALENT

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