Published in final edited form as:

Crit Care Nurs Clin North Am. 2000 June ; 12(2): 227–235.

Effects of Pediatric Head Trauma for Children, Parents, and Families

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SUMMARY

Severe pediatric head injury has negative consequences for children of all ages. Even mild and moderate head injury results in residual impairment for school-age children and adolescents. Data are needed on the effects of these less severe insults, especially for preschoolers. Although research on the impact of the child's head injury on the parent-child relationship and family functioning is limited, the experience is likely to be very stressful for the parent and the family. Indeed, family integrity may be at risk. Research is needed that examines the effects of a child's head injury for the parent and the family over time and identifies factors related to these outcomes.

Accidental injury is the leading cause of death and acquired disability for children over 1 year of age. Children under 15 years of age account for 22.4% of over 35 million emergency department visits each year that result from injury.⁴² Head injuries account for 29% of children's hospitalizations caused by injury.³⁴ Most pediatric head injuries are caused by accidental falls and motor vehicle accidents for 1- to 9-year olds and sports injuries for 5- to 9-year olds.²⁸ Continued progress in emergency medical care has led to increased survival of children with traumatic brain injury, but many survivors are at high risk for acute and chronic impairments in functioning. Thus, brain-injured children and their families face significant challenges because of impairment that affects the children's daily lives, their school performance, their future, and frequently, the well-being of family members and the family system.

When a preschool child suffers an accidental head injury, families are suddenly faced with fears about the child's survival and current condition and uncertainty about the child's future. Hospitalization in a pediatric intensive care unit (PICU) may exacerbate these fears.^{64, 66} Severely brain-injured school-age children and adolescents are often left with significant disabilities.¹⁶ Even school-age children and adolescents with mild traumatic brain injuries experience decreased functional status initially and problems with neurobehavioral abilities, such as attention deficit and memory loss, for at least a year after the injury.⁴⁷ The stress associated with adapting to a "new" child with continuing but subtle deficits is likely to have negative effects for the parent's mental health, with potential deterioration of the parent-child and family relationships. The purpose of this article is to review the research on effects of head injury for the injured child, the parents, and the family.

Effects on Injured Children

Although significant cognitive and behavioral disabilities after head injury have been documented in adult survivors, the effects of head injury on children have been overlooked because of the belief that children's brain elasticity would compensate for deficits caused by injury.⁵³ Alberico et al.¹ found that children had lower mortality rates and a higher percentage of good outcomes than adults with head injury of similar severity. However, even children with good outcomes may be discharged with significant impairments such as seizures, speech or gait problems, weakness in extremities, hearing or vision changes, and third nerve palsy.²⁷ Klonoff et al.,²⁶ in the first prospective follow-up of children after head injury, found that school failure and special educational placements were higher than expected in children with histories of head injuries before 9 years of age.

School-age children who sustained head injuries during their preschool years have a substantially increased risk for subsequent behavior disorders that interfere with school performance.³⁷ In one of the few studies focused on head injury in infants and preschoolers, Ewing-Cobb et al.¹⁰ found that infants and preschoolers who sustained a severe closed head injury scored lower on general cognitive measures, motor functioning, and expressive and receptive language measures during hospitalization and at 8 months postinjury. Effects of injury severity did not differ by age.

Research on postdischarge outcomes for school-age children and adolescents has included follow-up of cognitive development, academic performance, memory, functional abilities, health problems, and disability measured as long as 5 to 7 years postinjury. The extent of the disability varies with the severity of the head injury and time since injury. As with adults, significant functional impairments may be apparent even when standard IQ tests register normal abilities because standard cognitive assessments frequently measure skills learned before the head injury. Neuropsychologic assessments of memory, attention, and speed of information processing for new learning, however, are often more sensitive indicators of the effects of head injury than standard IQ tests.¹³

Both injury severity, as measured by the Glasgow Coma Scale (GCS), and neuropsychologic performance 3 months after head injury have been shown to predict special educational needs.²⁴ Donders found better performance IQ in children (10 to 17 years old) having mild or moderate head injury compared with severe head injury, but verbal IQ and memory did not differ with severity.⁸ Research by Kaufmann et al.²³ with 7- to 16-year-olds at 6 months postinjury produced similar results for severity of injury. In addition, they found poor attention with longer duration of impaired consciousness. In another study,⁶¹ 82.5% of children 4 years old or older and 92.5% of children 5 to 17 years old were disabled at discharge. Of the 156 children seen at 6 months postdischarge, 84 (53.8%) continued to be disabled. Limitations in the younger children were in physical activity and self-care. Massagli, et al.³⁶ also found continuing deficits at 5 to 7 years postinjury, including deficits in mobility (36%) and self-care (30%); 70% of the children were enrolled in special education classes. Outcomes at 5 to 7 years postinjury were related to length of coma and severity of head injury measured by Abbreviated Injury Scores (AIS), Injury Severity Scores (ISS), and GCS scores at 24 and 72 hours after injury.

In a longitudinal study of 6- to 15-year-old children, Jaffe et al.^{19, 20, 35, 46} found that severity of injury was related to several tests of IQ, adaptive problem solving, memory, and academic performance at 3 weeks, 1 year, and 3 years after injury. Severity of injury was also related to social competence, teacher ratings of adaptive functioning, and global functioning.⁴⁸ Moderately and severely injured children had significantly lower verbal and performance IQ, adaptive problem solving, and academic performance than mildly injured

children; severely injured children also scored lower on memory and psychomotor performance measures.²⁰ GCS scores at time of injury and days to reach GCS score of 15 (normal) were strongly related to IQ measures, memory, and performance but not to independent living skills at 3 weeks and 1 year after injury for children with severe head injury.³⁵ Children with mild head injury had significant deficits in eating, domestic, and home and community living skills at 3 weeks but not at 1 year after injury compared with normal controls. Younger school-age children had more deterioration in functioning during the first 3 months postinjury, whereas 12- to 16-year-olds showed more deterioration between 1 and 3 years postinjury.⁴⁸ The rate of improvement, however, diminished dramatically between 1 and 3 years postinjury.²⁰

In addition to school outcomes, severity of head injury has also been related to behavior and health problems after injury. In a sample of 45 children, ages 3 to 15, Fletcher et al¹⁴ found that greater injury severity was related to greater deficits in adaptive behavior and communication, more school problems, and less participation in sports and recreation activities as reported by parents. Rivara et al⁴⁹ found that injury severity was related to teachers' and interviewers' ratings of child behavior problems but not to parents' ratings.

Although head-injured 5- to 15-year-old children had more behavior problems at 1 year after injury, Greenspan and MacKenzie¹⁶ found no relationship between head AIS score and behavior scores, except for hyperactivity, which increased with higher AIS scores. Head AIS scores were related to limitations in role, physical abilities, and self-care. Over half (55%) of the parents in that study¹⁶ reported child health problems, including headaches; musculoskeletal or peripheral nerve problems; weakness and ataxia; and problems with vision, speech, or hearing. In another study,⁶ parents reported their 2- to 14-year-old children who had had mild head trauma (who were not hospitalized) continued to have physical complaints at 1 month after injury, including headache and vomiting, change in appetite, problems with speech or vision, walking difficulties or unsteady balance, and limitation in daily activities and play.

In summary, these studies provide consistent evidence for impairments after mild, moderate, and severe head injury. The effect of age on impairment is not clear, however, because Wesson et al⁶¹ found that younger children have less residual impairment than older children, but Michaud et al³⁷ found that school-age children who were injured as pre-schoolers were 8.8 times more likely to have behavioral disorders at school age than children who were injured in the school-age years. Although Kaufmann et al²³ suggest that time since injury interacts with the age of child, this does not account for the discrepancy. Both Wesson et al⁶¹ and Kaufmann et al²³ studied effects at 6 months after injury. Less is known about head trauma for pre-school children.

Epidemiologic data indicate that children with head injury differ from the general population and from children with other chronic health conditions on a number of characteristics related to outcomes. They are more likely to be of low socioeconomic status, to have preexisting learning or behavioral problems, and to come from families with significant dysfunction,⁷ but none of these studies controlled for the effects of factors such as socioeconomic status, race, and number of children and parents in the family, which often are found to be related to children's development. In addition, the emotional context for the child's recovery, including parent mental health, parents' reactions and perceptions, and available resistance resources, also has not been considered.

Effects on Parents

Research on the effects of the child's head injury on the parents is extremely limited. Caregiver research suggests that providing care to an impaired family member is stressful.

Caregivers of impaired elders or spouses report more illness symptoms, particularly those caused by respiratory infections, than non-caregivers, despite decreased exposure to pathogens.²⁵ Schultz and Williamson⁵¹ suggested that chronic stress from caregiving may exacerbate existing physiologic vulnerabilities or predispositions to conditions such as hypertension and cardiac arrhythmias.

Several studies of caregivers and relatives of adults with head injury have found significant mental health effects. Mintz et al⁴¹ found that 52% of relatives reported at least mild to moderate depression, and 48% reported mild to moderate anxiety. Depression was greater for those whose relatives with head injury were living in residential facilities rather than at home. Kreutzer et al³⁰ also report psychologic distress in caregivers of head-injured adults; 50% had elevated distress scores, 33% had high anxiety scores, and 25% had high depression scores. The relationship of the caregiver to the head-injured adult had an effect on depression scores, with spouses having higher depression scores than parents. The number of behavior problems reported for the brain-injured adult and time since injury were related to caregiver stress and family functioning.²⁹

A growing body of developmental research has demonstrated that mothers of children with chronic health conditions experience significant psychologic distress and that the level of distress is often related to the severity of the child's health condition.⁵⁵ If parents become depressed, their own functioning will be impaired with the possible consequences of unemployment, child neglect or abuse, marital distress or dissolution, and their own accidental injury. Thus, providing care to an impaired child could negatively affect the parents' physical and mental health, resulting in increased health care costs.

Effects for parents are important not only for their own mental and physical health but also because of the relationship consistently found between a parent's reactions and the reactions of the child. Pessar et al⁴⁴ reported that acting-out behavior and emotional problems for children with a brain-injured parent were related to depression in the uninjured parent and compromised parenting performance by either parent.

Parental anxiety has been related to the anxiety of school-age children during hospitalization and to child psychologic upset after discharge.^{4, 15, 56} In older experimental studies where the intervention provided some type of support to the mother, children in the experimental group showed fewer negative reactions postdischarge than children in the control group, probably because of decreased maternal anxiety.^{62, 63} These results suggest that parent mental health has an effect on the child's mental health.

Studies of parents' reactions to their child's hospitalization suggest that parents experience a variety of emotions and have many needs and concerns. Parents of 3- to 16-year-old head-injured children reported needing clear information, therapy input, and understanding from professionals and classroom teachers.⁶⁰ Parents of PICU children have identified a large number of physical, psychologic, and social needs during their child's stay. These include needing to receive frequent, accurate, and truthful information;^{12, 31} to be with the PICU child; to sleep in a place near the child; to participate in the child's care; and to know that the child was getting the needed treatment and care.²² Parents also identified a variety of stressors, such as uncertainty about the illness, caregivers, rules of conduct, and ward routines.⁵⁹ Some of the uncertainties led to misconceptions that increased the parent's stress or anxiety.

Several researchers have investigated parental concerns during PICU hospitalization of a child. Scott⁵² studied the needs of parents as perceived by the parents and the critical care nurses of children from newborn to 15 years of age who were hospitalized in a PICU. Information, assurance, and proximity to the child were identified as priority needs of the

parents. Although nurses identified similar parental needs, they rated the need for child-related information and hopefulness higher than parents did.

Lawson et al³³ found that parents' primary concern early in a child's PICU stay was the child's medical condition, specifically the uncertain prognosis. They experienced helplessness, shock, and disbelief and a lack of information or inability to assimilate the information that was provided. Parents clearly demonstrated signs of a physiologic stress response, which decreased over time. At 24 to 36 hours after PICU admission, parents rated their concerns about the child's future (survival, physical or mental impairment) highest.^{64, 66}

Parents with previous PICU experience had higher expectations for their child's recovery during the PICU stay than parents without previous experience.⁵⁸ After their child's transfer to the general care unit, parents reported increased anxiety and fear and feelings of isolation.³³ At 1 to 3 months after hospital discharge, parents identified finances as the major source of stress.³³ They felt guilty about neglecting the child's siblings and were still reliving the PICU experience, especially at night. These parents reported difficulty in finding supportive and understanding listeners.

In a series of three studies describing specific parental stressors during a child's PICU stay at different points in a child's illness, Miles and Carter, et al^{5, 9, 40} consistently found that the child's behavior and emotions and alterations in parental role were the two greatest stressors. A subsequent study produced similar results.³⁹ Higher stress scores were related to higher trait anxiety, lower parental age, higher perceived severity of illness, younger child age, more ICU visitation, and a perception of inadequate pre-PICU preparation.³⁸ In a study by Johnson et al,²¹ parents' greatest stressors were child behavior and emotions and procedures, and there were no differences for pre-PICU preparation. Interestingly, nurses rated each stressor dimension higher than parents did.

Higher parent anxiety has been related to aspects of the child's admission that are common in head injury admission. In a sample of parents with children in the PICU, Johnson et al²¹ found that anxiety levels were similar for mothers and fathers and for parents of children with medical or surgical admissions, but anxiety levels were higher for parents who had not received pre-PICU preparation by nurses than for parents who did. In another study,³⁸ greater anxiety was associated with an unexpected admission, greater perceived illness severity, and greater stress about role alterations, child behavior, and child appearance. Berenbaum and Hatcher² found that mothers of PICU children were significantly more anxious than mothers with general care unit (GCU) children and mothers with children seen in the outpatient clinic for minor acute illnesses. Higher anxiety was related to greater perceived illness severity and more negative family life stressors; greater perceived illness severity was also related to greater confusion, depression, and anger. LaMontagne et al³² found a decrease in anxiety from 24 to 48 hours after admission (Time 1) to 72 hours after admission (Time 2). Parents who used fewer problem-solving strategies and more escape avoidance had higher anxiety at Time 1 and Time 2. Greater use of social support at Time 1 and greater use of distancing at Time 2 were related to lower anxiety scores.

In addition to the stressors of hospitalization, a number of investigators have considered family adjustment an important consideration in understanding the long-term consequences of pediatric head injury. Marital problems, parental anxiety, and deterioration in family functioning have been documented in the postinjury period.^{3, 47, 50, 53} These family problems, and those often present before injury, may adversely affect the child's recovery from the head injury.

Family adaptation to the child's head injury is further complicated by its unique nature. Initially, family coping is directed to the child's survival and physical recovery, but neuropsychologic deficits may cause significant functional disabilities in motivation, ability to learn new information, and behavioral and social capabilities, even after the child physically appears to have recovered to his or her premorbid condition.^{53, 55} Because of this frequent discrepancy between functional improvement and physical normalcy, the National Head Injury Association calls head injury the *silent epidemic*. Only recently has head injury been recognized as a disability in the absence of frank mental retardation and physical handicap. For many parents, a lack of understanding of the nature of head injury can lead to inappropriate expectations of the child and misinterpretation of child behavior, creating a cycle of frustration and family conflict.

Parent–Child and Family Effects

Research on the effect of a child's head injury and hospital admission on the family is minimal. In a study of 5- to 16-year-old children (n = 92) with traumatic injury (not exclusively head trauma), Hu et al¹⁸ found that families who reported that their family had returned to normal by 6 months postinjury had children with higher levels of functioning and fewer behavior problems. These families were less likely to have a mother who developed psychiatric disorders during the child's hospitalization or a child who was still in rehabilitation therapy. Disrupted families were four to five times more likely to be single-parent families at 6 and 12 months after injury.

At 1 and 4 years after hospital discharge, Harris et al¹⁷ contacted parents of 50 children who sustained severe multisystem injury to assess family responses to the child's injury. Almost one third of the families reported worsening of the marital relationship. Financial problems were great: 58% of the families reported that at least one family member quit his or her job to care for the injured child, and 20% of the families had either spent their savings or gone into debt. Uninjured siblings were adversely affected as well, with 46% reported to have emotional disturbances, school problems, or aggression. In 16 families (32%), an estranged parent returned to the family, and in 4 (8%), the parental dyad separated or divorced. In 27 families (54%), parents reported an altered relationship between the parent and the injured child.

Rivara et al⁴⁷ followed children and their families longitudinally after head injury using both standardized measures and interviewer ratings of family functioning. Parents did not report changes over time, but increasing difficulties in family relationships over time were identified for families whose children had severe head injury.

Rivara et al⁴⁷ also found that the severity of the child's injury was related to degree of stress, quality of relationships, coping, and investigator ratings of global family functioning at 12 months postinjury. Families with severely injured children had greater deterioration from 3 to 12 months in psychologic strain and well-being and child–sibling and child–peer relationships. Although there was a slight decrease in investigator ratings of global family functioning for families with severely injured children, changes in scores on the objective family functioning measures—Family Environment Scale (FES), Family Inventory of Life Events (FILE), and the Coping Health Inventory for Parents (CHIP)—from 3 to 12 months were not significant. This discrepancy could be caused by the differences between insider and outsider perspectives on the family, although weaknesses in study design could also account for the conflicting findings.

Research on the effects of pediatric hospitalization (ignoring type of illness or injury) on the family is similarly limited. Ferrell et al¹¹ found that some families of children with cancer believed the child's experience brought the family closer together, although other families

thought the illness caused relationships to be strained and distant. In a study of 50 parents of 30 PICU children after the child's third PICU day,⁴⁵ parents had significantly higher cohesion scores but similar adaptability scores, when compared with published norms. Mothers' adaptability scores, but not their cohesion scores, were significantly higher than fathers' adaptability scores. Although it is not clear whether the mother-father comparison was done within families, which would strengthen the results, or across families, these findings suggest families experienced PICU admission as very stressful.

Youngblut and Shiao⁶⁷ measured family functioning at 24 hours after PICU admission and at 2 to 4 weeks after hospital discharge with a small sample of two-parent families. Mothers' cohesion scores decreased significantly from Time 1 to Time 2. Both mothers and fathers scored their families as significantly more adaptable than published norms, though cohesion scores did not differ significantly. Greater length of hospital stay was related to greater satisfaction with the family for fathers. The longer the child was intubated, the lower the mother's perception of family cohesion and the greater her dissatisfaction with the family. In a subsequent cross-sectional study, Youngblut and Lauzon⁶⁵ compared 27 families whose child under 5 years old had been hospitalized in the PICU and 25 families whose child had been hospitalized on the GCU. Families in the PICU and the GCU groups did not differ on their ratings of their family's cohesion, adaptability, and satisfaction with relationships, even when time since discharge was controlled. Longer hospital stays and greater severity of illness, however, were related to lower family cohesion ratings by fathers, and greater severity of illness scores and being in the PICU group were related to lower adaptability by mothers.

Implications for Practice

Children with head trauma continue to have behavior, learning, and academic problems after hospital discharge. The extent of persistent problems is related to the severity of the injury; however, even children with mild head injury report physical symptoms for a month postdischarge and may have some behavioral problems over the first year postinjury. Nursing care for these children includes assessing and monitoring for these symptoms during the hospital stay and at outpatient visits after discharge. In addition, anticipatory guidance with the parents should focus on the length of time that the child's symptoms may continue and stress the need for assessment by the health care team throughout the child's first year postdischarge. With close monitoring, interventions to control or diminish the child's symptoms can be initiated early in the postdischarge period.

During the hospital stay, parents of head-injured children experience considerable distress and anxiety. Providing frequent, truthful, clear, and accurate information may decrease these negative emotions. In addition, opportunities to participate in the child's care and permission or encouragement to stay close to the child may also allay the parents' anxiety and distress. After discharge, parents continue to require monitoring because they are at risk for depression, distress, and anxiety. This may be especially true for mothers whose child's injury was more severe. Identifying parents who are having significant problems with depression or distress and helping them seek treatment are critical to the parent's health and functioning and, thus, to the child's health and well-being.

Finally, it is important to remember that all members of the family may be affected by the child's injury. Well siblings may experience a variety of problems, including emotional disturbances, school problems, and aggression. Financial problems may occur because of health care expenses or the loss of a job by one or more of the family's members. In addition, in some families, the marital couple's relationship worsens; in others, it improves. Discussing these possibilities before discharge, identifying resources for each potential

problem, providing early referrals to these potential helpers, and encouraging families to use them when necessary may allow the family to better plan for the child's discharge and the first few months postdischarge.

Acknowledgments

This article was funded by the National Institute of Nursing Research, National Institutes of Health, Grant # R01-NRO4430.

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