



Research Roundtable Summary

16

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in a Series of Seminars

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Research Projects

Recovery from Traumatic Brain Injury in Children

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Reaction

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About This Series

The Research Roundtable Series, sponsored by the Maternal and Child Health Bureau (MCHB), disseminates the results of MCHB-funded research to policymakers, researchers, and practitioners in the public and private sectors. The results of these projects influence future service, research, and policy development. The Research Roundtable sessions provide an opportunity for researchers to discuss their findings with policymakers, MCH program directors, service providers, and other health professionals.

The Maternal and Child Health Research Program is directed by Dr. Gontran Lamberty and administered through the Division of Systems, Education and Analysis, MCHB, Health Resources and Services Administration (HRSA). HRSA is a component of the Public Health Service (PHS), part of the U.S. Department of Health and Human Services (DHHS). The purpose of the research program is to support applied research relating to maternal and child health services that shows promise of making a substantial contribution to the advancement of those services.

Introduction

Dr. Gontran Lamberty introduced the speaker and the reactor for the Research Roundtable. Dr. Taylor is a professor in the department of pediatrics at Case Western Reserve University School of Medicine and a neuropsychologist in the division of behavioral pediatrics and psychology at Rainbow Babies and Children's Hospital. His research interests include the study of the consequences of high-risk conditions arising in infancy and early childhood, with a focus on the followup of children with meningitis, leukemia, head injury, and low birthweight. Dr. Taylor currently serves as a reviewer for the Behavioral and Neurosciences Special Emphasis Panel for the National Institutes of Health and is a special reviewer for the Maternal and Child Health Bureau Research Grants Review Committee.

Dr. Shapiro is an associate professor in the University of Minnesota Departments of Neurology and Pediatrics and is an adjunct associate professor in the department of psychology and the Institute of Child Development. Dr. Shapiro is also the director of the pediatric neuropsychology unit.

Presentation

Statement of the Problem

Children who sustain moderate-to-severe traumatic brain injury (TBI) are at high risk for a variety of long-term neurobehavioral sequelae. TBI in a child is an enormously stressful event for the family. Families are faced with a heavy burden of care and have to make immediate emotional adjustments, especially in cases in which the injury affects the child's behavior or cognitive abilities. Family resources may be stretched and schools are frequently ill-prepared to meet the child's special needs. Clinical followup of children suggests that family dysfunction may lead to persistent behavior and learning problems in spite of cognitive recovery. Unfortunately, few efforts have been made to examine the impact of pediatric TBI on families in a systematic fashion or to determine if the extent of the child's recovery is influenced by the post-injury family environment.

Research Questions and Hypotheses

The primary objectives of the project were to test two hypotheses regarding sequelae of TBI for children and their families. The first hypothesis was that moderate-to-severe TBI adversely affects the family social environment and leads to more parental psychological distress than traumatic orthopedic injuries that do not involve insult to the central nervous system (CNS). Due to the persistence of cognitive and behavioral sequelae of TBI, it was hypothesized that these differences would be apparent throughout the first year following injury. It was also hypothesized that the impact of both types of injuries on families would vary with sociodemographic status, concurrent family stressors and resources, and parental coping strategies.

The second hypothesis was that post-injury family characteristics predict outcomes at 6 and 12 months after injury for children with TBI, even after injury severity and pre-injury child and family status are taken into account. It was also hypothesized that family variables would predict changes in outcomes across followup. Although family factors were hypothesized to predict outcomes for children with either TBI or orthopedic injuries, the more negative family consequences of TBI were expected to contribute to group differences in sequelae.

Goals were to (1) examine the effects of brain insult and family factors on different types of child outcomes (e.g., behavior versus cognitive functioning); (2) increase understanding of factors that contribute to the emergence of behavior disorders following brain insults in children; (3) survey the impact of orthopedic trauma on children and their families; (4) discover ways that families are affected by and cope with both forms of injury; and (5) recognize factors that place individual children and families at high or low risk for adverse consequences. Clarification of risk and resistance factors is of special value in identifying high-risk children, documenting the relevance of family interventions in the rehabilitation process, and improving health care delivery following traumatic childhood injuries.

Study Design, Methods, and Population

The study design consisted of prospective followup of groups of children with severe TBI, moderate TBI, or orthopedic injuries not involving CNS insult. The rationale for including an orthopedic-injury comparison group was to control for (1) background factors associated with proneness to accidental injury and (2) the hospitalization experience. The orthopedic injury group also provided a control for the practice effects inherent in repeated testing.

The population from which the project sample was drawn included school-age children with traumatic injuries. Specific criteria for inclusion in the sample were that children (1) be hospitalized for at least 1 night's duration for either moderate-to-severe TBI or orthopedic trauma not involving

CNS insult, (2) be between 6 and 12 years of age at injury, (3) show no evidence of child abuse or previous neurological disorder, and (4) reside in an English-speaking household. Children with brain insults that did not fall into the general category of closed head injuries (e.g., brain injury due to near-drowning or toxins, projectile wounds, stroke) were excluded. Children with TBI were classified into a moderate or severe group. Severe TBI is defined on the basis of a Glasgow Coma Scale (GCS) score at admission of 8 or less. Moderate TBI is defined in terms of an admission GCS score of 9–12 or a GCS score of greater than 12 accompanied by a skull fracture, intracranial mass lesion or contusion, diffuse cerebral swelling, posttraumatic neurologic abnormality (e.g., seizures, hemiparesis), or documented loss of consciousness of greater than 15 minutes. Although many children in the TBI group had accompanying orthopedic injuries, the orthopedic injury group was limited to children without symptoms suggestive of possible CNS insult (e.g., concussion, severe facial trauma). To provide for sufficient sample sizes, children were recruited from four hospitals in Ohio.

The children and their parents were seen on three occasions during the first post-injury year. The first, or baseline, assessment was administered a mean of 3 weeks post-injury. For children in the TBI group, recovery from posttraumatic amnesia was required prior to the baseline testing. Estimates of pre-injury child and family functioning were based on teacher and parent ratings collected at or before the baseline assessment. Assessments of child and family outcomes were then readministered at 6 and 12 months after the baseline evaluation. All three groups of children and their families were followed in an identical manner.

Measures of outcome included ratings of child behavior and tests of achievement and neuropsychological abilities. A short form of the Wechsler Intelligence Scale for Children (3rd edition) provided a measure of overall intelligence; this short form consisted of the verbal subtests Similarities and Vocabulary and the performance subtests Block Design and Object Assembly. The Test of Nonverbal Intelligence was administered to obtain a measure of overall nonverbal reasoning skills. Tests of language abilities included the Boston Naming Test, Work Fluency Test, and portions of the Clinical Evaluation of Language Fundamentals–Revised. Tests of perceptual motor skills included the Developmental Test of Visual–Motor Integration and the Grooved Pegboard Test. To assess verbal and nonverbal memory abilities, the California Verbal Learning Test was administered. Measures of attention and executive function consisted of the Contingency Naming Test, Underlining Test, and Continuous Performance Test. The Woodcock-Johnson Psycho-Educational Battery–Revised was used to assess academic achievement. Subtests administered included Letter/Word Identification, Passage Comprehension, Dictation, Applied Problems, Calculation, and Writing Samples.

The injury's impact on the family was assessed by having parents complete ratings and interviews with regard to family functioning, the perceived family burden from the injury, and the parents' psychological distress. Measures of child behavior and learning and of the family environment prior to injury permitted assessment of injury consequences relative to pre-injury status. The Parent Report of Child's Educational Progress, completed via parent interview, provided information regarding the child's educational history and current school program. The teacher version of the form, Teacher's Report of Child's Educational Program, requested similar information and was sent to teachers for completion. Parents were also interviewed about the child's delay in school reentry following injury. This information is relevant to policymaking and educational planning. Also examined were relationships between school placements and child outcomes.

Measures of child behavior and psychosocial adjustment included the Child Behavior Checklist, Teacher's Report Form, Walker-McConnell Scale of Social Competence and School Adjustment, Children's Depression Inventory, and Neurobehavioral Symptom Checklist. Also administered were the measures of posttraumatic stress disorder, including the Post-Traumatic Stress Reaction Index, which is based on a child's self-report, and the Post-Traumatic Stress Scale, based on

the parent's report. To assess adaptive behavior, the Vineland Adaptive Behavior Scales were used.

Data on health outcomes were obtained on the Child's Health and Health Care Utilization Form. The first section of this form consists of the Child's Health Status Scale. The second section contains the Activities Restriction Scale, adapted from the National Health Interview Survey. The final section contains the Health Care Utilization Scale, which documents the type and amount of health care received over the previous year.

Research Findings

The findings from the project provide strong support for both hypotheses. Consistent with the first hypothesis, families of children with TBI reported a higher level of burden and psychological distress than did families of children with orthopedic injuries. Within the TBI group, the amount of burden and distress was greater for families whose children had more severe TBI. Even at 1 year post-injury, 42 percent of parents in the severe TBI group reported clinically significant levels of psychological distress compared with 30 percent of the moderate TBI group and 20 percent of the orthopedic injury group. Similarly, 34 percent of families in the severe TBI group and 16 percent of those in the moderate TBI group reported a level of burden at the 12-month followup, as based on the Family Burden of Injury Interview. Group differences were significant at the 12-month followup, even after race and sociodemographic factors were controlled for. The latter finding is consistent with reports of persisting distress in families of adults with TBI.

Data from the Family Burden of Injury Interview, developed as part of this project, also showed that much of the burden on families was related to the psychological aspects of adjustment to childhood injury (e.g., worry about the child, sibling reactions, communicating with spouse and others). Information from parent interviews further revealed that parents seldom recognized the need for help with their adjustment problems.

Results from the present study also confirmed the possibility of identifying families most likely to be adversely affected by pediatric TBI. Analyses of baseline data reveal that parental distress following TBI was associated with both pre-injury family stressors and maladaptive parental coping styles, even after injury severity and sociodemographic factors were controlled for. Analyses of the 12-month followup data yield similar findings. Controlling for injury severity and sociodemographic status, researchers found that families with higher levels of chronic stressors and fewer social resources reported more family dysfunction at the 12-month followup. Preliminary analysis further revealed that preexisting family stressors contributed more to the perceived burden of injury for parents of children with TBI than for parents of children with orthopedic injuries—a finding consistent with the “vulnerability” or “adversity producing” model of stress adaptation.

In accordance with the second hypothesis, the behavior and cognitive sequelae of TBI were predicted both by pre-injury environmental risk and by the impact of the injury on the family. These relationships held even after sociodemographic status, race, and injury severity were taken into account. Family factors, therefore, appeared to be contributing to recovery independent of injury severity. In some instances, family factors had a significantly greater impact on children with TBI than on children with orthopedic injuries. This finding suggests that children with TBI are particularly vulnerable to family distress and dysfunction or that the process of recovery from TBI is more susceptible to family influences than other, more normative age-related changes. However, it is not yet clear if the children who are manifesting greater neurobehavioral effects are imposing more burden on their families or if family adversity is contributing to negative child outcomes. The working hypothesis is that the relationship is bi-directional. Analyses are currently being done to test this hypothesis and examine the influence of potential moderating factors, such as social supports, family resources and stressors, and coping styles on relationships between family and child outcomes.

Analyses to date have revealed that the family environment is affected by injury and that family and child consequences are interrelated. Preliminary analyses have further demonstrated that families' responses to injury are to some extent predictable and that it is possible to identify families at greater risk for problems in adaptation to injury. Families in which there was a greater degree of dysfunction and fewer resources prior to injury reported more injury-related burden after injury. Post-injury parental coping styles characterized by maladaptive responses (e.g., disengagement) were also associated with more negative family outcomes.

The study provides valuable new information regarding the impact of orthopedic trauma on children and their families. The findings not only document the negative impact of traumatic injuries on children's families, but also help to delineate the nature and sources of negative family impact. In addition, study results demonstrate that pre- and post-injury family status is, in fact, associated with the child's long-term recovery. The major implication of these findings is that treatment of childhood traumatic injuries is likely to be facilitated by attending to both child and family needs.

The present results suggest a number of specific ways to reduce child and family morbidity of traumatic childhood injuries. First, the impact of injury on the family can be reliably assessed with methods such as the Family Injury of Burden Interview. This measure is sensitive to the difficulties experienced by families following a traumatic childhood injury, and is also useful for delineating specific family needs and in directing clinical interventions. In view of the evidence that one cannot count on parents to express their emotional needs, reduction in family morbidity is likely to require a system of anticipatory guidance and routine followup care.

Second, it is impossible to identify children and families at highest risk for adverse consequences of injury and hence to target the families most in need of careful followup. Risk status for families is related to the severity of the child's injury, preexisting family stresses, and family coping styles. Risk factors contributing to more negative child outcomes include injury severity, preexisting family dysfunction and stress, poor family adaptation to the injury, developmental or behavior problems prior to injury, and evidence of neurobehavioral symptoms soon after injury. Findings from the present study suggest that the ultimate outcome for the child is determined by several of these factors operating in conjunction with one another, rather than by a single overriding factor such as injury severity.

Third, the list of neurobehavioral symptoms developed as part of the project was a particularly good predictor of adverse child and family outcomes. This or similar symptom checklists hold substantial promise as a means for identifying children most in need of careful followup and comprehensive post-injury assessments.

Fourth, there are psychosocial and family consequences of orthopedic trauma. Therefore, children with traumatic injuries not involving brain insult per se are also in need of clinical followup and family interventions.

Fifth, children with TBI frequently have periods of protracted recovery involving substantial delays in school reentry. Furthermore, there is a lack of uniformity in approaches to assisting the children in school reintegration and in treatment of academic and behavior problems. Many high-risk children received little if any special consideration. These findings suggest a need for (1) an increased appreciation by schools of the problems and needs of children with TBI, and (2) the creation and implementation of policies on educational programming for these students.

Reaction

Dr. Shapiro complimented Dr. Taylor on his research and its contribution to the study of children's recovery from TBI. Dr. Shapiro described one of her patients, a 13-year-old girl who had a TBI, and related how Dr. Taylor's research could provide valuable information about the management

and treatment of the girl and her family. Dr. Shapiro felt that this was a landmark study detailing the environmental and social factors on recovery of TBI patients.

Dr. Shapiro felt that the most significant strength of this study was its use of social and familial factors as predictors and outcome variables. The study was very well designed, with an appropriate control group. Another important study strength was that the family burden interview looked at the impact of disease.

Limitations of the study were few. Dr. Shapiro suggested that future research in this area should include neuroimaging data and recognize the effects of gender and age. More details about behavioral abnormalities in Dr. Taylor's study would have been helpful.

Education for parents and schools, support in coping for the children with TBI and their caregivers, and direct self-management help for children are all issues that Dr. Shapiro feels need to be confronted. Dr. Shapiro also stressed that future research should be directed toward the effects of rehabilitation and the development of tools to measure neurobehavioral abnormalities. Parents need guidance in how to adjust to a changed child, and schools need advice in developing programs that better address the special needs of this population.

Discussion

Participants discussed the medication management of children with severe TBI and the effects of stimulants on behavior. Participants also noted that careful behavioral followup of the children at regular intervals after the injury may be helpful in determining how behavior is affected and in distinguishing more biologically related behavioral changes from changes that may reflect environmental influences. Further discussion focused on the important role that parent support groups can play in helping families adjust to a child with severe to moderate TBI. The role of the educational system in evaluating and educating children following injury was discussed; teachers and others working with these children may need additional training to better understand the complexities of brain injury.

Publications

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