



Research Roundtable Summary

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NINTH

in a Series of Seminars

on MCHB-funded

Research Projects

Psychosocial Sequelae of Bronchopulmonary Dysplasia and Very Low Birthweight

June 27, 1995 • Parklawn Building, Conference Room K

Lynn Singer, Ph.D.

Professor

Departments of Pediatrics and Psychiatry

Case Western Reserve University School of Medicine

Reaction

Zolinda Stoneman, Ph.D.

Director

Georgia University Affiliated Programs for Persons with Disabilities

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For more information, please contact Michelle Keyes-Welch, NCEMCH, (703) 524-7802.



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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, Maternal and Child Health Bureau, 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. Lynn Singer is a professor in the departments of pediatrics and psychiatry at Case Western Reserve University School of Medicine. Dr. Singer's research interests include the developmental and behavioral sequelae in infants and children as a result of chronic illness, low birthweight, and cocaine exposure.

Dr. Zolinda Stoneman is director of the Georgia University Affiliated Programs for Persons with Disabilities. Dr. Stoneman is well known for her research on the effects of developmental disabilities, family processes, and child temperaments on sibling relationships. Dr. Stoneman is also a member of the Maternal and Child Health Bureau Research Grants Review Committee.

Presentation

Statement of the Problem

The specific long-term consequences of very low birthweight (VLBW) and the way in which families adapt to and influence the outcomes of their VLBW infants have become important medical and developmental research questions over the last decade. In the United States, approximately

40,000 children per year are born weighing less than 1,500 grams. The number of survivors has increased seven times in this birthweight category over the last 20 years, due in part to surfactant and other medical advances in perinatology. Survival, which was once the exception, has affected the long-term morbidity of the childhood population. While many of these children are healthy, a subgroup experience significant disabling conditions and/or chronic illnesses.

Previous studies have shown that infants with severe chronic lung disorders of prematurity are likely to develop a number of negative developmental consequences later in life, including increased incidence of respiratory infections, poor growth, impaired intellectual and social development, and feeding problems. However, these studies usually had very small sample sizes (less than 30 patients), and findings have been inconsistent. Also, surfactant or steroids are a relatively recent advancement in medicine, and therefore were not used in older studies of VLBW infants. Previous studies were often conducted before the onset of the cocaine epidemic; since 25–40 percent of the VLBW cohorts have experienced fetal cocaine exposure, drug exposure is an important yet overlooked factor in studying this population.

Research Questions or Hypotheses

This study focused on the developmental and family sequelae of bronchopulmonary dysplasia (BPD) and the medical and psychosocial complications of prematurity and VLBW. BPD is one of the few chronic illnesses that can be identified at birth, so this study was able to look longitudinally at the infant and family. Most studies on chronic illness and disability look at older infants and children, since these conditions often are not diagnosed immediately following birth.

The research team hypothesized that, in comparison with a control group of full-term, healthy infants and a control group of VLBW infants without BPD, infants with BPD would (1) exhibit more developmental problems when assessed on standard measures of growth and intellectual, motor, and language development; (2) have parents show higher degrees of depressive symptomatology and stress; and (3) exhibit more deviant and maladaptive feeding behaviors.

Study Design and Methods

The study employed a prospective, longitudinal, quasi-experimental design with measures administered at intake, at 40 weeks of age, and at 8, 12, 24, and 36 months of age corrected for prematurity. A medical and demographic data base was established for all infants.

Infants and parents were assessed separately with several psychological instruments. Physical measurements of the infants, including measures of stunting and wasting, were also taken. In addition, infants were videotaped during a feeding session and these tapes were scored. A second meal observation was scored based on behavioral observations. Mothers were asked to complete a food diary, and a play session was rated for maternal warmth, control, and child involvement.

Population Description and Sampling Plan

The study included 122 infants with BPD (defined for this study as preterm infants weighing less than 1,500 grams who were oxygen-dependent for more than 28 days following mechanical ventilation during the first week of life, and with persistent increased densities on chest radiographs) and their caregivers. Also included were 84 VLBW comparison infants without BPD, matched for gestational age and birthweight, and 123 term comparison infants (both groups ranging in age from newborn to 2 years). The majority of infants were African American. Infants who had congenital malformations or who had mothers with psychiatric illness or HIV were excluded.

Findings

At birth, infants with BPD were smaller and sicker and had more neurologic problems than VLBW infants without BPD, despite the incorporation of surfactant and steroids into medical care practices. At followup, infants with BPD had a higher incidence of cerebral palsy and visual and hearing problems, and had significantly lower mental and motor scores than VLBW infants and term infants at all ages. At 2 years, incidence of mental and/or motor retardation was 25–27 percent in the BPD group, compared with 10 percent of VLBW infants without BPD and an expected rate of less than 3 percent in term infants. BPD was an independent predictor of lower IQ and poorer motor development after all other medical and demographic factors were controlled for.

Contributors to child developmental outcome that might be mediated/moderated by BPD include associated biological factors, poor feeding and growth, chronic illness, and parental adaptation. The research team documented an increased occurrence of repeated hypoxic episodes during early feedings in healthy BPD infants. This problem can affect feeding behaviors as well as neurological outcome. Also, BPD infants had more feeding problems neonatally, despite the increased efforts of their mothers, whereas VLBW infants without BPD achieved “catchup” caloric intake with similarly increased efforts from their mothers.

In terms of psychological and parenting stress, there were significant group and parent differences. During the neonatal period, mothers of both BPD and VLBW infants without BPD had significantly higher psychological distress levels than term mothers and reported increased use of alcohol and drugs as coping mechanisms. At 8 and 12 months, distress levels for all groups were within normal limits, but at 2 and 3 years, mothers of BPD infants had increased distress compared with mothers of VLBW infants without BPD, and this distress was related to lower infant IQ. Mothers of children with BPD described their children as more easily distracted and hyperactive.

Fathers did not differ during the neonatal period, but by 1 year fathers of BPD infants reported increased distress. For both mothers and fathers of BPD infants, child-related parenting stress increased over time. Maternal depressive symptoms were related to decreased responsivity during feeding in VLBW mothers, but not in term mothers.

Because the incidence of VLBW is disproportionately affected by fetal cocaine exposure, the research team followed an additional group of cocaine-exposed VLBW infants. These infants had increased rates of out-of-home placement, more intraventricular hemorrhage at birth, and increased risk for developmental delay, all of which posed special problems for the delivery of medical care and followup.

Reaction

Dr. Stoneman commented on the study’s real-world impact and its ability to provide important data on psychosocial issues for families adjusting to infants and children with chronic illnesses and/or disabilities. The study sample was large enough to permit an examination of interactions and the confounding of variables, something lacking in earlier studies.

Dr. Stoneman noted that the study received multiple-agency support, a clear indication that the principal investigator and funding agencies worked collaboratively to bring a strong study to fruition. Dr. Stoneman felt that the study was scientifically sound and commended Dr. Singer for studying fathers and their interactions and stressors. Fathers are often overlooked in maternal and child health research.

Dr. Stoneman suggested that the project might take a more indepth look at the children eligible for Part H early intervention services and how eligibility interacts with what services the families and children are actually receiving. Dr. Singer has collected some general data on this, but a

more comprehensive analysis would be helpful in assessing the impact of early intervention services. The impact of managed care on the family's ability to access intervention services is another area that could be explored more indepth in a followup study.

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