



Completed Projects

1999-2000

Maternal and Child Health **RESEARCH PROGRAM**

U.S. Department of Health & Human Services
Public Health Service



Maternal and Child Health **RESEARCH PROGRAM**

Completed Projects 1999 and 2000



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Preface

Safeguarding and improving the health of mothers and children is a demanding national responsibility. It requires significant expenditures of funds, highly trained and dedicated professionals, private and State-supported professional schools to educate new practitioners and update seasoned clinicians, systems of vital statistics, and laboratory and hospital data to monitor morbidity and mortality when and where they happen. Above all, safeguarding and improving the health of mothers and children requires an expanding scientific knowledge base and the means for scientists and practitioners to draw upon this knowledge quickly and accurately.

Research is the mechanism that expands our scientific knowledge base. Our knowledge base is expanded when new knowledge is generated or existing scientific information is validated or rejected. These activities do not materialize overnight, and at the research project level, they often do not produce more than modest gains in knowledge.

Quality research requires more than the application of the scientific method to data collection and careful monitoring of research in the laboratory or the field. With few exceptions, it is essential that each research proposal be peer reviewed and assessed at the planning stage for originality, importance, and technical quality. Only research proposals that can pass this scrutiny should be approved and funded, since they involve a significant commitment of national resources. When completed, the research project should again meet the standards of peer review before the findings are published in professional journals—a prerequisite for acceptance by the scientific community.

After being accepted by the scientific community and incorporated into the knowledge base, research findings need to advance to the application stage. As with formulating and executing research, translating research findings into clinical application calls for careful planning, imaginative thinking, and hard work. Publishing findings in scientific journals does not automatically lead to clinical application. Sometimes, professional inertia may delay application of new findings; at other times, the potential for clinical application may not be fully realized. Not infrequently, an additional piece of knowledge may be needed in order to apply a body of findings to clinical settings. Often, research findings are not applied in health care delivery settings simply because prospective users are not aware of new findings—a problem addressed through this continuing series of MCH research publications.

About This Publication

This edition of completed research abstracts, the seventh in the series, is a companion volume to *Maternal and Child Health Research Program: Active Projects*. The volume of completed abstracts informs MCH practitioners and scientists of the availability of findings from the MCHB-supported research projects whose principal investigators submitted a final report to the Research Program during 1999-2000.

The research projects in this book are arranged alphabetically by project name. This edition features a project classification system to help readers understand the nature of each research project at a glance. Each study is classified according to the Healthy People 2000 objectives addressed, study design, time design, care emphasis, population focus, and racial/ethnic focus (if applicable). The completed projects are also indexed by title and by research topic at the back of this book.

We believe this publication will promote increased knowledge as well as enlightened discussion of state-of-the-art research in the field of maternal and child health.



Project Classification Guide

Each project in this book is classified according to the Healthy People 2000 objectives addressed, study design, time design, care emphasis, racial/ethnic focus (if applicable), and population focus. These categories are described below.

Healthy People 2000 Objectives

This category lists the Healthy People 2000 objective(s) addressed by the project. The number of the objective(s) is listed for each abstract and a complete listing of the objectives corresponding to these numbers is provided in the appendices of this book.

Study Design

The study designs are divided into three subcategories: (1) Experimental, which includes randomized clinical control trials; (2) quasi-experimental, which includes case/matched control, case/unmatched control, case/historical control, and interrupted time-series studies; and (3) observational, which includes studies that are purely descriptive or seek to elucidate cause and effect associations without the investigator actually seeking to control the situations under which these associations unfold or take place.

Time Design

This category includes three components: (1) Cross-sectional, (2) longitudinal, and (3) mixed. Cross-sectional studies describe or examine cause and effect relationships through measurements taken at one point in time. Longitudinal studies, however, seek to ascertain through serial measurements how cause and effect associations change or do not change over time. Mixed studies are those that include both longitudinal and cross-sectional components.

Care Emphasis

This category distinguishes between interventional and noninterventional studies. In interventional studies, the investigator, through a particular effort, treatment, or program, seeks to purposively influence the outcome(s) in an individual or a group. In noninterventional studies, the investigator merely observes, measures, and describes a situation without purposively manipulating or seeking to alter in any way the ensuing outcomes.

Population Focus

This category describes the investigation's primary population, including age, gender, family role, and pregnancy status dimensions or characteristics. The particular dimensions and subdivisions within these stated dimensions or characteristics (i.e., neonates, preschool children, pregnant women, etc.) are specific to maternal and child health program issues and concerns.

Race/Ethnic Focus

This classification sorts projects according to whether they are able to describe or elucidate issues related to race and/or ethnicity status, using either a within-group or a between-group study format. Studies that do not fall under this definition are classified as having no racial/ethnic focus.

**Completed
PROJECTS ABSTRACTS**





African-American Children's Transition to School

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Project Number MCJ-370649

NTIS Number PB2000-106924

Project Period 10/1/1994-9/30/1999

Costs	Direct Costs Awarded	Indirect Costs Awarded	Total
Year 1	106,020	47,179	153,199
Year 2	119,187	53,038	172,225
Year 3	142,384	63,361	205,745
Year 4	147,757	65,752	213,509
Year 5	150,980	67,186	218,166

Year 2000 Objectives

8.3, 17.15, 20.9

Study Design

Observational

Time Design

Longitudinal

Care Emphasis

Noninterventonal

Population Focus

School-aged Children,
Parents/Families/Mothers/Fathers (Adolescent
Parents)

Race/Ethnic Focus

African Americans

Summary

Statement of the Problem

During the first few years of elementary school, children, families, and schools should be mutually adapting to enhance the academic success of children and to encourage the family's involvement in their child's schooling. This is especially important for African American children from low-income families because many low-income African American children are at risk for school difficulties. Spending one's childhood in poverty reduces a child's potential school and adult attainments. Even after adjusting for measurable characteristics associated with poverty (living with a single parent, less educated parents, or parents with less prestigious jobs), the detrimental effects of poverty are clear. In the United States in 1996, 20.5% of children under six years of age were poor, and 39.9% of African American children lived in poverty (The State of America's Children Yearbook, 1999). A better understanding is needed of the processes through which poverty leads to later under-attainment in school for some African American children.

Many African American children succeed in school despite the fact that they are raised in the presence of one, two, or several risk factors. Parents, other adults, siblings, and peers can play a buffering role for African American children who might otherwise be considered at risk. A growing body of research suggests that the presence of social support networks for parents

indirectly enhance socio-emotional functioning among low-income African American children (McLoyd, 1990). Determining protective factors that buffer African American children from risk in school is needed. Further, more knowledge is needed of the child, family, and community factors during early childhood that help children succeed and protect them from experiencing school failure.

Research Questions or Hypotheses

The purpose of this research project was to examine the risk and buffering factors and mediators (child care and the role of parenting) that affect children's outcomes and transition to school during the first three years of elementary school. The specific aims of this study were to: (a) determine the multiple determinants of language, cognitive, social, and academic skills of African American children in early elementary school years within an ecological model of child development; (b) identify how risk and protective factors affect children's success or failure in school; and (c) describe the developmental trajectories of African American children's language, cognitive, and social development and academic achievement from infancy through the early elementary school years.

Study Design and Methods

Seventy-four African American children (39 girls, 35 boys) were enrolled in the project. All children had participated in an earlier research project examining the relationship of otitis media with effusion (OME) and associated hearing loss in early childhood to children's later language development. Children were initially recruited from community based child care centers between 6 and 12 months of age (mean = 8.2 months) and had no known medical or genetic abnormalities when entering the study. Upon study entry in infancy, 73.3% of the families were low-income households according to the federally defined poverty and the primary caregiver had completed 12.5 (SD = 2.1) years of education. In the earlier study, from infancy until kindergarten entry, children's middle ear status was assessed bi-weekly and hearing status every three months and when ill with OME. Behavior, language, cognitive, and emergent literacy skills were assessed annually, as was quality of child care and responsiveness of home environment. In the present study, children's language, academic skills, behavior, family environment, and classroom environment were assessed annually before entering kindergarten and at the end of kindergarten, first grade, and second grade.

Findings

Preschool outcomes. Results indicated that the number of social risk factors (e.g., living in poverty, stressful environment) present in a child's environment was significantly related to measures of children's language and cognitive skills during the first three years of life. Higher quality child care and child cares that met professional recommendations regarding child-adult ratios during the first 3 years of life had children with higher scores on measures of language development across time. The elaborativeness of the mothers' language independently related to children's receptive language skills at 1 year of age. Children from more stimulating and responsive homes were also reported to have higher scores on language measures during the preschool years. Both the home and child care environments also mediated the relationship between OME/hearing loss children experienced during the first two years of age and children's cognitive and language skills at 1 and 2 years of age. A history of OME and associated hearing loss was not associated with language skills during the preschool years, but a mild association was present with school readiness measures at entry into kindergarten. Although we found a very mild association between OME and school readiness, the quality of the home and child care environments provide a much stronger prediction of children's school readiness skills.

School age outcomes. Study results indicated that the responsiveness of the home environments and quality of the child care environments influenced children's language development and emergent literacy skills at entry to kindergarten. Early childhood child and family characteristics were also related to reading and math scores at the end of first grade. Analyses also support the role of language and emergent literacy skills at school entry in affecting children's school performance at the end of first grade. Children's emergent literacy skills at entry into kindergarten mediated the relationship between family background factors and children's reading skills at the end of first grade. Children with better reading skills at the end of first grade tended to enter kindergarten with better emergent literacy skills. Likewise, children's language skills at entry into kindergarten mediated the relationship between family background factors and children's math skills at the end of first grade. Children with better math skills at the end of first grade tended to enter school with stronger language and emergent literacy skills and had mothers who were able to communicate information more clearly during a school-like task.

Recommendations

1. Children, especially those from families living in poverty, should receive high quality child care. High quality child care requires child-adult ratios such as recommended by the American Public Health and American Pediatric Associations (1992) to permit the extensive teacher-child interactions that promote responsiveness. In addition, teachers providing high-quality care are trained to be responsive and contingent in interacting with young children and to provide a developmentally appropriate curriculum.
2. Modifying aspects of the social and home environment that are modifiable (e.g., responsiveness of the mother, family stress) and that families are interested in changing may improve children's language development, emergent literacy, and later academic achievement. Parent education to facilitate a more supportive and responsive home environment may be beneficial for children.
3. Given that children's skills at entry to kindergarten were predictive of later reading and math skills and that trajectories for school success are typically established by the time children are in third grade (Alexander & Entwistle, 1988; Pianta & Walsh, 1996), children need to be as prepared as possible for the challenges of school beginning in kindergarten.
4. Study results provide some support for strategies for management of young children who experience OME such as monitoring OME and hearing and speech and language screening.

Products To Date

Articles

- Hooper SR, Burchinal MR, Roberts JE, Zeisel SA, Neebe EC. 1998. An application of the cumulative risk model. *Journal of Applied Developmental Psychology* 19(1):85-96.
- Robert JE, Wallace I. 1999. Otitis media and later language and learning. *Seminars in Otitis Media Management* 2(1):10-15.
- Roberts JE. 1999. Otitis media and hearing loss: Is child development affected? *Seminars in Otitis Media Management* 2(1):1-2.
- Roberts JE, Burchinal M, Durham M. 1999. Parents' report of vocabulary and grammatical development of African American preschoolers: child and environmental associations. *Child Development* 70(1):92-106.
- Roberts JE, Burchinal MR, Jackson SC, Hooper SR, Roush J, Mundy M, Neebe EC, Zeisel SA . 2000. Otitis media in childhood in relation to preschool language and school readiness skills among black children.. *Pediatric* 106(4):725-735.
- Wallace IF, Roberts JE, Lodder DE. 1998. Interactions of African American infants and their mothers: Relations with development at 1 year of age. *Journal of Speech, Language and Hearing Research* 41:900-912.
- Zeisel SA, Roberts JE, Neebe EC, Riggins R, Henderson FW. 1999. A longitudinal study of otitis media with effusion among 2- to 5-year-old African American children in child care. *Pediatric* 103(1):15-19.

Presentations

- Cardwell AM, Roberts JE. 1998. *Early literacy practices and African American preschoolers' narrative skills*. Presented at the Annual Convention of the North Carolina Speech, Hearing, and Language Association, Charlotte, NC.
- Dickinson D, Roberts JE. 1998. *Language, literacy, and school success: Linkages between home and school*. Presented at the Annual Convention of the American Speech, Language and Hearing Association, San Antonio, TX.
- Gravel JS, Roberts JE, Roush J, Wallace IF, Ellis MA, Lee WW, Mundy M. 1999. *Hearing in 10-36 month olds with OME from two geographically-diverse prospective cohorts*. Presented at the Seventh International Symposium on Recent Advances in Otitis Media, Fort Lauderdale, FL.

Gravel JS, Roberts JE, Roush J, Wallace IF, Ellis MA, Lee WW, Mundy M. 1999. *Hearing in 10-36 month olds with OME from two geographically-diverse prospective cohorts*. Presented at the Seventh International Symposium on Recent Advances in Otitis Media, Fort Lauderdale, FL.

Jackson SC, Roberts JE. 1998. *Complex syntax production and language skills of African American preschoolers*. Presented at the Annual Convention of the North Carolina Speech, Hearing and Language Association, Charlotte, NC.

Jackson SC, Roberts JE. 1998. *Narrative styles and literacy skills of African American preschoolers*. Presented at the Annual Convention of the American Speech, Language and Hearing Association, San Antonio, TX.

Jackson SC, Roberts JE. 1999. *Complex syntax production and language skills of African American preschoolers*. Presented at the Annual Convention of the American Speech, Language, and Hearing Association, San Francisco, CA.

Jackson SC, Roberts JE. 2000. *Complex syntax production of African American preschoolers*. Presented at the Fourth Biennial Memphis Research Symposium: Communication and Literacy in African American Children and Youth, Memphis, TN.

McLelland J, Roberts JE. 1998. *Storybook interaction of African American mothers and their children*. Presented at the Annual Convention of the American Speech, Language and Hearing Association, San Antonio, TX.

Price J, Jackson SC, Roberts JE. 2000. *Narrative development of African American 4- and 5-year-olds*. Presented at the Fourth Biennial Memphis Research Symposium: Communication and Literacy in African American Children and Youth, Memphis, TN.

Roberts JE. 1996. *Carolina otitis media project and African American children's transition to school*. Presented at the 42nd Annual Convention of the North Carolina Speech, Hearing, and Language Association, Charlotte, NC.

Roberts JE. 1997. *Otitis media in early childhood and preschool children's language skills*. Presented at the Society for Research in Child Development, Washington, DC.

Roberts JE, Bryant D, Burchinal M, Jackson S, Zeisel S. 1998. *African American children's transition to school: Role of child, family, and child care factors*. Presented at the Head Start's Fourth National Research Conference: Children and Families in an Era of Rapid Change, Washington, DC.

Roberts JE, Burchinal MR, Zeisel S. 1998. *Use of the short form of the Communicative Development Inventory with African American infants and families*. Presented at the 1998 International Conference on Infant Studies, Atlanta, GA.

Roberts JE, Grave, J, Jackson S. 1999. *Otitis media and auditory processing and language sequelae*. Presented at the Annual Convention of the American Speech, Language, and Hearing Association, San Francisco, CA.

Roberts JE, Gravel J, Schwartz RG, Dollaghan C, Campbell T. 1998. *Does otitis media cause speech and language sequelae?* Presented at the Annual Convention of the American Speech, Language and Hearing Association, San Antonio, TX.

Roberts JE, Jackson S, Burchinal M, Zeisel SA. 2000. *Child, family, and childcare factors: Predictors of African-American children's school transition*. Presented at the Head Start's Fifth National Research Conference, Washington, DC.

Roberts JE, Jackson SC, Burchinal M. 1999. *Otitis media and children's later narrative skills*. Presented at the Seventh International Symposium on Recent Advances in Otitis Media, Fort Lauderdale, FL.

Roberts JE, Jackson SC, Burchinal M. 1999. *Otitis media and children's later narrative skills*. Presented at the Seventh International Symposium on Recent Advances in Otitis Media, Fort Lauderdale, FL.

- Roberts JE, Rosenfeld R, Zeisel SA, Derbenwick E. 1999. *Does otitis media contribute to language sequelae? A meta-analysis of prospective studies*. Presented at the Seventh International Symposium on Recent Advances in Otitis Media, Fort Lauderdale, FL.
- Roberts JE, Rosenfeld R, Zeisel SA, Derbenwick E. 1999. *Does otitis media contribute to language sequelae? A meta-analysis of prospective studies*. Presented at the Seventh International Symposium on Recent Advances in Otitis Media, Fort Lauderdale, FL.
- Roberts JE, Wallace I, Zeisel S, Jackson S. 1999. *Otitis media and language and learning sequelae during the preschool years*. Presented at the Biennial Meeting of the Society for Research in Child Development, Albuquerque, NM.
- Roberts JE, Zeisel S, Burchinal M, Neebe E. 1999. *Otitis media and parent and teacher ratings of children distractibility and hyperactivity*. Presented at the Seventh International Symposium on Recent Advances in Otitis Media, Fort Lauderdale, FL.
- Roberts JE, Zeisel S, Burchinal M, Neebe E. 1999. *Otitis media and parent and teacher ratings of children distractibility and hyperactivity*. Presented at the Seventh International Symposium on Recent Advances in Otitis Media, Fort Lauderdale, FL.
- Roberts JE, Zeisel SA. 1997. *A longitudinal study of the communication of African American children using the MacArthur Communicative Development Inventory*. Presented at the Society for Research in Child Development, Washington, DC.
- Roberts JE, Zeisel SA, Jackson SC, Burchinal M. 1998. *Otitis media and later preschool language and academic outcomes*. Presented at the Seventh International Symposium on Recent Advances in Otitis Media, Fort Lauderdale, FL.
- Roberts, JE, Zeisel, SA, Jackson, SC, Burchinal M. 1999. *Otitis media and later preschool language and academic outcomes*. Presented at the Seventh International Symposium on Recent Advances in Otitis Media, Fort Lauderdale, FL.
- Swartzfager J, Roberts JE, Medley LP, Frazier M. 1995. *Impact of home and childcare environment on children's language development*. Presented at the Annual Convention of the American Speech-Language-Hearing Association, Orlando, FL.
- Swartzfager JL, Roberts JE, Medley LP. 1995. *Communication and symbolic behavior scales: Assessing African American infants/preschoolers*. Presented at the 41st Annual Convention of the North Carolina Speech, Hearing, and Language Association (NCSHLA), Greensboro, NC.
- Zeisel SA, Roberts JE, Burchinal M, Neebe E. 1999. *Risk factors for otitis media during the first 5 years of life*. Presented at the Seventh International Symposium on Recent Advances in Otitis Media, Fort Lauderdale, FL.
- Zeisel SA, Roberts JE, Burchinal M, Neebe E. 1999. *Risk factors for otitis media during the first 5 years of life*. Presented at the Seventh International Symposium on Recent Advances in Otitis Media, Fort Lauderdale, FL.



Clinician Help for Mothers of Infants with Lung Disease

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Project Number MCJ-550806

NTIS Number PB2000-106926

Project Period 10/1/1995-9/30/1998

Costs	Direct Costs Awarded	Indirect Costs Awarded	Total
Year 1	171,533	73,759	245,292
Year 2	175,856	74,438	250,294
Year 3	182,892	78,644	261,536
Year 4			
Year 5			

Year 2000 Objectives

2.4, 14.14

Study Design

Experimental

Time Design

Longitudinal

Care Emphasis

Interventional

Population Focus

Neonates, Infants,
Parents/Families/Mothers/Fathers (Adolescent
Parents)

Race/Ethnic Focus

African Americans

Summary

Statement of the Problem

Infants of extremely low birth-weight (ELBW, <1250 grams) are increasing in number. Their risk for neurodevelopmental and medical problems, including chronic lung disease, requires mothers to develop caregiving competencies that are sensitively attuned to and responsive to their special needs. These competencies include relating to the infant and providing sensitive and responsive behavior during feeding interaction, constructing expectations and intentions for caregiving that are sensitive and responsive to the infant's short- and long-term needs, and communicating and problem solving effectively with clinicians about infant health issues. Even though these competencies may make a difference to infant health outcomes (e.g., feeding behavior, nutrient intake, growth, and development), few treatments to support the development of a mother's caregiving competencies through the infant's first post-term year have been examined.

Guided participation is a practice in a social setting (hospital, home, clinic). Through this practice, a more experienced, resourceful person (e.g., a nurse) supports a less experienced, resourceful person (e.g., a mother of an ELBW infant) who must become competent in a socially important activity (e.g., caregiving).

This study was a longitudinal randomized clinical trial of the effectiveness of guided participation, compared to standard

care, in supporting mothers in developing caregiving competencies for their ELBW infants (birth weight < 1250 grams). The caregiving competencies we focused on were in the following three domains: (a) relating to the infant; (b) giving care adaptively (e.g., interacting with the infant during feeding in a sensitive and responsive manner; having adaptive expectations about and intentions for caregiving in the context of feeding; and (c) communicating and problem solving with the infant's primary-care physician. The five infant health-related outcomes examined in this study were: (a) the quality of an infant's regulation of affect and behavior during feeding; (b) caloric intake; (c) feeding skills; (d) weight-for-age z score; and (e) motor development.

Research Questions or Hypotheses

The first objective of the study was to examine the effectiveness of guided participation, compared to standard care, for supporting mothers in developing caregiving competencies and enhancing infant outcomes. We tested the following hypotheses related to this objective:

1. Guided participation, compared to standard care, will have a direct effect on infant outcomes (feeding behavior, feeding skills, caloric intake, growth in weight, and motor development).
2. Guided participation, compared to standard care, will have a direct effect on three aspects of a mothers' caregiving competencies: (a) regulating negative affect and feeding behavior; (b) constructing an adaptive working model of caregiving in the context of feeding, expressed in expectations and intentions for infant feeding; and (c) effectively communicating and problem solving with the infant's primary care physician.
3. The mother's caregiving competencies will mediate the effect of guided participation on the infant outcomes.

The second objective was to explore the cost of acute illness care for infants in both study groups. The analysis for this objective is in process.

Study Design and Methods

The effectiveness of guided participation, compared to standard care, was examined in a longitudinal randomized clinical trial. Of 57 consenting families (mothers and their ELBW infants), the 45 families that contributed data at two or more assessment points constituted the sample. ELBW infants and their mothers were drawn from the eligible population of 80 families whose infants were patients at one of three tertiary nurseries in the Milwaukee area. Infants weighed 1250 grams or less at birth and were appropriate weight for gestational age. Mothers were English-speaking and 17 years of age or older. Families were randomized into either the guided participation (GP, treatment) group or the standard care (SC, alternative treatment) group. GP, directed by written protocols, began in the special-care nursery after the family had signed the consent form and continued at home through 12 months PTA. An advanced practice nurse led the guided participation with a family through the study period.

Both the GP and SC groups received the care usually offered in the special care nursery and community to ELBW infants and their families. Both the GP and SC groups received inhome assessments at approximately 1, 4, 8, and 12 months, infant post-term age (PTA). A mother's competency in regulating negative affect and behavior during feeding was assessed with the Parent-Child Early Relational Assessment (PCERA) from a video-taped feeding at 1, 4, 8, and 12 months, infant PTA. The adaptiveness of her expectations and intentions for feeding her infant was assessed from an audio-recorded and transcribed interview at 1 and 12 months, infant PTA. A mother's competencies in communicating and problem solving with the infant's primary-care physician was assessed by this physician at approximately 4 and 12 months PTA using eight 9-point rating scales.

At each of the four in-home assessments, the infant's weight was obtained. Feeding skills were assessed during the feeding as being present or absent. A measure of caloric intake was obtained from the 3-day prospective food record kept by the mother. The quality of the infant's regulation of negative affect and behavior was assessed with the PCERA after the visit from the video-tape of the observed feeding. The Bayley Scales of Infant Development-II (BSID-II) were used in the home by an occupational therapist to obtain a Psychomotor Development Index (PDI) score at approximately 4 and 12 months PTA. The infant's risk for neurodevelopmental problems was assessed in the home with the Bayley Infant Neurodevelopmental Screener by the nurse data collector at 8 months PTA.

To study differences between treatment groups in costs of acute illnesses, Medicaid data for billings for health-care for infants in the study have been obtained through the State of Wisconsin Bureau for Health-Care Financing. These data are being completed with the costs of health care paid by private insurers.

Longitudinal structural modeling (Lisrel) was the data analytic strategy used to address the research hypotheses. A path analysis using a non-iterative procedure, two-stage least squares, was used to estimate parameters of relationships among

variables.

Findings

We found that guided participation, compared to standard care, did not have a significant direct effect on any of the five infant outcomes that we selected to study. The test of the first hypothesis was limited by too little power to detect a true alternative to the null hypothesis of no difference between guided participation and standard care treatment groups. The power was reduced by the considerable variability among infants in both groups on outcome variables.

We expected a relationship of the guided participation on a mother's caregiving competencies, proposed in the second hypothesis, because the treatment was primarily targeted to these competencies. We found that guided participation, in contrast to standard care, contributed significantly and positively to a mother's competencies in regulating negative affect and behavior during feeding at 4 months post-term age. This competency concerns qualities of a mother's social-emotional and task-related feeding behavior that are likely to aid the infant's feeding (e.g., the mother's affect and behavior increases the likelihood of a positive feeding experience for the infant). A significant contribution of guided participation to the adaptiveness of a mother's caregiving expectations and intentions in the context of feeding and to her competencies in communicating and problem solving with the infant's primary care physician, as assessed by the physician, was not demonstrated.

In part, measurement issues may have contributed to the lack of a significant guided participation effects on two of the caregiving competencies we examined. The adaptiveness of a mother's caregiving expectations and intentions at 1 month PTA may have been assessed too early in the mother's experience of her infant's feeding for an effect of guided participation to be demonstrated. The primary-care physician's rating of a mother's competencies in communicating and problem solving at 4 months PTA may have been biased by the difficulties that caring for an ELBW infant with a relatively low weight-for-age z score are likely to present to a mother.

The third hypothesis concerned the test of the mediation of caregiving competencies on the relationship of the treatment with the infant outcomes. One or more significant effects of all three caregiving competency variables on three infant outcomes (weight-for-age z score, PDI, and the dysregulation and irritability of feeding behavior) were found. The relationship, at 4 months infant PTA, of a mother's competency in regulating negative affect and behavior during feeding with both the infant's weight-for-age z score and the PDI were negative. The relationship, at 4 months infant PTA, of the primary-care physician's rating of a mother's competency in communicating and problem solving with the infant's weight-for-age z score was also negative. In contrast to these unexpected negative relationships, an infant's feeding behavior was less dysregulated and irritable, as predicted, the more adaptive a mother's caregiving expectations and intentions were. This relationship was significant at $p = .051$.

The unpredicted negative effect for the relationship of a mother's competency in regulating negative affect and behavior during feeding with both the infant's weight-for-age z score and the PDI may be due to the operation of other variables not included in the system of variables we examined. Or the negative effect may indicate that the qualities of regulated affect and behavior during feeding generally thought to support infant growth in weight and motor development may not be appropriate for supporting this growth and development in infants of extremely low birth weight. Another potential explanation of the negative relationship is that mothers of the infants lowest in the weight-for-age z score and in psychomotor development may work harder to regulate negative affect and feeding behavior.

Due to the lack of a significant total effect of the treatment group on whatever infant outcome was included in the system of variables examined, a mediating effect on the relationship of treatment group and outcome could not be claimed for any of the three caregiving competency variables. Again, the major issue in determining whether or not the caregiving competencies have a mediating effect is the limited power to detect an effect of the treatment group on infant outcomes.

Recommendations

Guided participation is a method of supporting a mother's development of competencies for care of an ELBW infant that requires, primarily, an ongoing, highly individualized but systematic practice. Although study findings were limited by power issues, the results of tests of guided participation effectiveness on a mother's social-emotional and task-related caregiving competencies (i.e., regulating negative affect and behavior), compared to standard care, are promising enough to suggest several recommendations.

Both hospital and community-based resources for guided participation need to be developed. These resources potentially include both hospital nurses and public health nurses. Mothers of ELBW infants may need support of caregiving competencies beyond that traditionally offered prior to the infant's discharge from the special-care nursery. This support may

need to continue through much of the infant's first post-term year. Ongoing challenges in caregiving are likely to be encountered due to the infant's biologic condition and developmental changes. Mothers may need to encounter caregiving issues and accrue experience in day-to-day caregiving and in arranging and managing health care for their infants to take advantage of guided participation. Guided participation is premised to operate on the experience of the person who is developing a practice.

To make full use of guided participation, mothers are likely to require mental health and adequate stability in their personal lives. A family therapist, parent aid, and/or care coordinator could help a mother obtain this stability and should be thought of as potential members of a team in a system of guided participation.

Further tests of the effectiveness of guided participation with a larger sample are indicated. In addition, refined data collection-instruments and measurement processes are indicated. The protocol for guided participation should be strengthened and focused in respect to each domain of caregiving competencies.

Products To Date

Articles

Pridham K, Limbo R, Schroeder M, Thoyre S, Van Riper M. 1998. Guided participation and development of caregiving competencies for families of low birth-weight infants. *Journal of Advanced Nursing* 28:1948- 1958.

Presentations

Limbo R, Pridham KF. 1999. *Guided participation: A method of learning in natural settings*. Presented at the Third Biennial International Nursing Conference, Madison, WI.

Pridham K, Schroeder M, Limbo R. 1997. *A program to support the feeding of premature infants*. Presented at the Focus '97 National Pediatric Conference, Milwaukee, WI.

Pridham K, Schroeder M, Limbo R., Thoyre S, Brown R, Steward D. 2000. *Feeding skill progression of premature infants*. Presented at the International Conference on Infant Studies, Brighton, United Kingdom.

Pridham KF. 1998. *Support of family caregiving for children with special needs*. Presented at the Parenthood in America National Conference, Madison, WI.

Steward, DK, Pridham KF. 1999. *Risk of growth failure in extremely low birthweight infants*. Presented at the 23rd Annual Research Conference of the Midwest Nursing Research Society, Indianapolis, IN.



Crossing Cultural Boundaries: An Ethnographic Study

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Project Period 1/1/1997-12/31/1999

Costs	Direct Costs Awarded	Indirect Costs Awarded	Total
Year 1	133,730	61,940	195,670
Year 2	141,764	69,482	211,246
Year 3	143,774	70,515	214,287
Year 4			
Year 5			

Year 2000 Objectives

17.14, 17.20, 22.4

Study Design

Observational

Time Design

Longitudinal

Care Emphasis

Noninterventional

Population Focus

Infants, Toddlers, Preschool-aged Children,
School-aged Children

Race/Ethnic Focus

African Americans

Summary

Statement of the Problem

This ethnographic study followed 30 African American children with special health care needs, their families and the health care providers who served them. The purpose of this three-year study was to examine how the child's problem was variously understood or "framed" by family members and health care practitioners, the influence of different frames or misunderstandings on the intervention process, the processes undertaken by family members and practitioners to negotiate or impose alternative views, and the impact of these multiple perspectives on the effectiveness of interventions. The research team identified and examined clinical (and occasionally school-related) intervention events that were perceived by both providers and parents as successful as well as events that illuminated dilemmas or miscommunications that resulted in less effective treatment.

The projected outcomes of this study were the generation and dissemination of new knowledge in the following areas: 1) understanding of family perspectives on their experiences in caring and nurturing young children with special health care needs; 2) family, practitioner, and researcher perspectives on obstacles to integrated, coordinated services; 3) family, practitioner, and researcher perspectives on factors that contributed to successful collaboration; and 4) interpretation of the

misunderstandings and confusions that permeate services for a chronically under-served population, African American families from inner city neighborhoods.

Research Questions or Hypotheses

The key questions were these. What miscommunications occurred in clinical interactions and what were the consequences for the child's development? How did this miscommunication, which has been well documented in the case of minority clients receiving health care services from physicians (Garro, 1994; Good, 1993; Good & Good, 1979), present special difficulties to families who received interdisciplinary intervention services for their child with special health care needs? What were the obstacles that perpetuated the miscommunications and lack of access to health care services among low income ethnic minorities, specifically African American populations? What were the developmental consequences which resulted from miscommunication and collaborative breakdowns between providers and client caregivers? What were the beliefs and values of different key actors that led to communicative trouble and breakdown?

The central hypothesis of this study was that difficulties in collaboration between families and health care providers was a major contributing factor to ineffective treatment of inner city African American children with special health care needs. A further hypothesis was that poor collaborative relations were not merely the result of individual personality differences or differences in interpersonal interactional and communicable styles. Rather, the research team hypothesized that the most serious impediments would result from the different cultural worlds to which the professional and family "partners" belonged. The "clinic culture" in which health providers practice often differs markedly from family cultures in assumptions and expectations about: (a) the developmental needs of the child; (b) the role and responsibilities of family caregivers in supporting those needs; (c) the role of the professional "expert" in addressing them; and (d) the treatment approaches most effective in addressing the child's needs.

It should be noted that these hypotheses were offered in the context of an ethnographic study; therefore research was not directed to a narrow search for their confirmation or disconfirmation. Rather, the purpose of the study was to develop, modify and revise these hypotheses in light of the data collected.

Study Design and Methods

This study was characterized by those research design features which distinguish ethnography as a particular form of qualitative research: (a) a phenomenological and narrative theoretical orientation; and (b) a combined holistic and micro-ethnographic design. Exploration of differences in cultural expectations and meanings concerning the nature of illness and disability, child development, and family caregiving were combined with a micro-ethnographic study of provider/client/caregiver relationships as these played out in clinical encounters (based on observations and videotapes). Narrative interviews, focused interviews, participant observations, videotaping, and document reviews were conducted. In addition, this design incorporated an additional innovation that the research team described as "event-centered" analysis in which the perspectives of multiple actors (e.g., parent, therapist, physician) were collected related to key events or health care encounters. This study paid particular attention to the way personal and cultural meanings and experiences were organized in story form by the participants themselves. The study focused upon interpretive contexts from a specifically narrative perspective, analyzing the narrative structure of social action. The research team investigated the clinical encounter as a short story nested within much broader historical, cultural, and social contexts.

Audio taped open-ended and focused narrative interviews were conducted with health care practitioners as well as family members. Practitioner interviews focused on issues about their professional practices, beliefs, and background; as well as their perspectives related to the children and families in the study. Family interviews, conducted with the mother or primary clinic contact, and later with additional family members, focused on such topics as: illness narratives; (b) stories of parenting; (c) family history and genogram; (d) scenario building or narratives of the future; and (e) perspectives on relationships with health care professionals. In later phases of the study, interviews focused on clinical interactions which research team members had observed and, in many cases, videotaped.

Collective narratives comprised one key kind of data generated through collective interviewing with caregivers from subsets of the study cohort (eight to ten per session) who met periodically in groups with the research team. In this technique, illness and other key family narratives were produced not by a lone storyteller but in the social context of a group who told stories to one another and, in so doing, mutually shaped one another's individual narratives. Finally, narratively organized interviews with the primary caregivers generated family genograms (or pictorial representations of family organization across generations) (McGoldrick & Gerson, 1985). These interviews involved a mapping of family members, relational ties, household configurations, and demographic information (i.e., age, sex, educational level, health, job status, economical

level, and educational level). During the mapping process, the team moved toward a more narrative interview approach that enabled the emic categories from each family culture to emerge.

Team researchers carried out extensive observations (subsequently reported in field notes), and made multiple videotapes of clinical and home interactions for each case. A portion of the videotapes were also transcribed, serving as an in-depth form of observation data which supplemented field notes and allowed close analysis of interactions between practitioners, children, and family members. Videotaping also allowed other members of the research team to view interactions and analyze them in a way not possible on the basis of field notes alone.

Findings

The presentation and discussion of findings reported here reflects the natural progress of data analysis to date. The voluminous amount of data generated within this study will continue to be analyzed over time, serving to enhance and expand the research team's knowledge. Over the next several years, it is anticipated that additional reports, presentations and published articles will be generated by the research team as they continue to immerse themselves in the rich data derived within this study, and as they are able to compare the findings with those of subsequent research studies.

This research has allowed us to identify patterns across cases concerning the intersections of illness experience, adaptive processes, disability condition, characteristics of health care provision, and environmental factors. The research team has investigated patterns within caregiving units, such as the family, which also have tremendous theoretical implications. In this section, common themes that have emerged across the vast majority, or a significant portion of cases are briefly listed. In Section V: "Presentation and Discussion of Findings," examples are provided from the data to illustrate these points. While some findings presented here are discussions of the data that have already appeared in publications, are in press, or in manuscripts in preparation, other analyses are still preliminary.

1. The dynamic and shifting structure of family caregiving has a direct impact on partnering up with health care professionals.
2. Family configurations are often fluid and dynamic. This dynamic quality of family life also often characterizes family caregiving, including ~e "partnering up" of two or more parenting family members who function in caregiving teams. Fluid and shifting partnerships may result from reconfiguring due to changes in a child's or caregiver's health status.
3. The health status of the primary caregivers, and the health and well being of the child are intrinsically related. Caregivers themselves often suffer from chronic or serious health conditions that impede their ability to provide care for an ill or disabled child; they are "vulnerable caregivers." Furthermore, families frequently manage multiple illness trajectories. Fluidity in caregiving teams and adjustments in family priorities are sometimes the result of useful family adaptations to handle multiple chronic illnesses suffered by a child's primary caregiver or other key family members.
4. The illness or needs of the identified child may be a subplot to other unfolding family dramas or crises, thus compelling the child's key caregivers to shift attention away from the child or distribute attention across multiple significant needs.
5. Resiliency, resources, and supports may "buffer" hardships and suffering, but such resources are often not obvious. Family resiliencies are often subtle, detectable through observation of family life or engagement with family members. Thus, they are often hidden from the practitioner's view. Furthermore, aspects of institutional and professional cultures mask or limit a family's expression of resiliency, strengths, protective factors, economic resourcefulness, and family hardiness.
6. Race, ethnicity, and performing the "good parent" are central elements of clinical encounters from the perspective of many family caregivers. Family caregivers struggle to perform the "good parent" to practitioners as part of their effort to secure needed health services for their child. Assumptions about race, culture, ethnicity, social status, economic level, and education indirectly and powerfully influence health care encounters and the process of partnering up between families and professionals. Families report anxiety related to the need to perform "good parenting" in order to build partnerships with professionals.
7. The family and child's perspective on his or her illness or disability will change over time in relation to developmental progress, environmental supports and demands, and family adaptation. Families and health care practitioners deal with the child as a self who is "becoming."
8. The culture of the clinic, stressing caregiver compliance and measurable outcomes, can make it difficult for practitioners to build upon good connections with children and families over time.
9. Clinical teams routinely work to develop pictures not only of who a child is, or what a child needs, but of the family caregiving situation. Practitioners are engaged in a process of clinical constructions of family life.
10. Families are also characterized by their own cultures that are reflected in their patterns of caregiving, perspectives on the meanings of illness or disability, child rearing, and organization of family life.

Recommendations for Future Research: This study has made clear the need to understand how caregiving partnerships and therefore barriers to effective health care change over time in this population. This research exceeded the team's expectations, yielding a wealth of rich data both on the clinical world and family life. As in most in-depth ethnographies, this study unearthed a number of important unanticipated findings which suggest directions for further research. Most significant has been the dramatic and shifting reconfiguration of "caregiving teams" (that is partnering adults) who take responsibility for the family's dependents, the extent to which many caregivers are overburdened or "vulnerable" due to their own illness trajectories, and the ways family meanings associated with the illness or disability of the child intertwine with and depend upon other more pressing matters such that even severe illness may be but one sub plot in the midst of other concerns. Subsequent longitudinal research on family caregiving could help to further elucidate the shifting dynamics of family caregiving in this population.

Products To Date

Abstracts

Hunt LK, Mattingly C. 1999. Performing "race" and ethnicity in the crisis of the medical movement. *Abstracts of the American Anthropological Association*.

Lawlor M. 1999. Performing the "good parent". *Abstracts of the American Anthropological Association*.

Lawlor M. 2000. Cross-cultural collaboration: Performing the "good parent". *Abstracts of the III Conferencia de Pesquisa Socio-Cultural, Culture Brokering: Relating Health Care and Illness to Everyday Life*.

Marshall P, Mattingly C, Keonig B. 1997. Moral and practical reasoning in biomedicine and beyond. *Abstracts of the American Anthropological Association*.

Mattingly C. 1997. Narrative suspense and the lost self. *Abstracts of the Fourth Congress of the International Society for Cultural Research and Activity Theory: Activity Theory and Cultural Historical Approaches to Social Practice*.

Mattingly C. 1997. Thinking with stories: Narrative reasoning in clinical practice. *Abstracts of the American Anthropological Association*.

Mattingly C, Rouse C. 1999. Power, performance and race: Contested constructions of a dying child. *Abstracts of the American Anthropological Association*.

Articles

Hunt LM, Mattingly C. 1998. Introduction: Diverse rationalities and multiple realities in illness and healing. *Medical Anthropology Quarterly* 12(3):267-272.

Lawlor MC, Mattingly C. 1998. The complexities embedded in family centered care. *American Journal of Occupational Therapy* 52(4):259-515.

Mattingly C. 1999. Rewriting the self: History, memory and narrative (Mark Freeman): Book Review. *Transcultural Psychiatry* 36(4):513-515.

Mattingly C. 1998. In search of the good: Narrative reasoning in clinical practice. *Medical Anthropology Quarterly* 12(3):273-297.

Mattingly C, Lawlor M. 2000. Learning from stories: Narrative interviewing in cross-cultural research. *Scandinavian Journal of Occupational Therapy* 7(1):4-14.

Chapters

Fleming M, Mattingly C. 2000. Action and narrative: Two dynamics of clinical reasoning. In J Higgs and M Jones, eds., *Clinical Reasoning in the Health Professions* (2nd ed.). Oxford: Butterworth-Heinemann.

Mattingly C, Lawlor MC. 1998. Disability experience from a family perspective. In M Neistadt and E Crepeau, eds., *Willard & Spackman's Occupational Therapy* (9th ed., pp. 43-55). Philadelphia, PA: JB Lippincott.

Presentations

Burke JP, Lawlor M, Mattingly C, Cohn ES. 2000. Once upon a time...How narrative informs practice. Presented at the Annual Conference and Exposition of the American Occupational Therapy Association, Bethesda, MD.

Cohn ES, Crepeau E, Lawlor M, Mattingly C. 2000. Interpreting text: Exploring approaches to narrative analysis. Presented at the Annual Conference and Exposition of the American Occupational Therapy Association, Bethesda, MD.

Lawlor M. 1997. Crossing cultural boundaries. Presented at the Pediatric Therapy Network, Torrance, CA.

Lawlor M. 1997. The intersections of families and the clinical world. Presented at the American Occupational Therapy Foundation, Qualitative Research Exchange, Orlando, FL.

Lawlor M. 1998. Children as actors in the social world. Presented at the World Federation of Occupational Therapy, Montreal, Quebec.

Lawlor M. 1998. Crossing cultural boundaries: An ethnographic study of therapeutic experiences. Presented at the Department of Biokinesiology and Physical Therapy, University of Southern California, .

Lawlor M. 1998. Mind reading, scaffolding, and other intersubjective phenomenon. Presented at the Network for Non Scholastic Learning, Bietostolen, Norway.

Lawlor M. 1998. Reading minds in occupation: The intersections of development and occupational science. Presented at the American Occupational Therapy Foundation Research Colloquia, Baltimore, MD.

Lawlor M. 1998. Reflections on disability experiences. Presented at the Spina Bifida Clinic, Los Angeles, CA.

Lawlor M. 1999. Engaging moments: Co-conspiracies in social action. Presented at the Twelfth Annual Occupational Science Symposium, University of Southern California, .

Lawlor M. 1999. Family-centered care, . Presented at the Maternal and Child Health Sponsored Conference, USC and the University Affiliated Children's Hospital of Los Angeles, .

Lawlor M. 1999. The social construction of childhood occupations. Presented at the Panel on Children's Occupations from Multiple Perspectives, American Occupational Therapy Association, Indianapolis, IN.

Lawlor M. 1999. Who is learning? Who is teaching?. Presented at the Network for Non Scholastic Learning, Sondeberg, Denmark.

Lawlor M, Mattingly C. 1997. Analysis of practice - part 1. Presented at the Children's Hospital of Los Angeles, Los Angeles, CA.

Lawlor M, Mattingly C. 1997. Fantasy and imagination. Presented at the Children's Hospital of Los Angeles, Los Angeles, CA.

Lawlor M, Mattingly C. 1998. Clinical reasoning: Facilitating reflective practices. Presented at the 1998 Clinical Council, University of Southern California, Los Angeles, CA.

Lawlor M, Mattingly C. 1998. Reading minds and narrative time. Presented at the Daniel Freeman Hospital, Los Angeles, CA.

Mattingly C. 1998. Creating Pocohontas and other collaborative moments: Clinical encounters between and occupational therapist and her client. Presented at the Network for Non Scholastic Learning, Nordic Consortium (University of Aarhus and University of Copenhagen), Beitestolen, Norway.

- Mattingly C. 1998. Narrative and the construction of self. Presented at the World Occupational Therapy Conference, Montreal, Canada.
- Mattingly C. 1998. Senses of an ending: The self under threat. Presented at the Panel: Narratives, Emotions and the Self, Fourth Congress of the International Society for Cultural Research and Activity Theory: Activity Theory and Cultural Historical Approaches to Social Practice, University of Aarhus, Denmark.
- Mattingly C. 1999. Emergent narratives and the social construction of self. Presented at the Department of Philosophy, Aarhus University, Denmark.
- Mattingly C. 1999. Learning how to hope: African-American parents and children with disabilities. Presented at the Network for Non Scholastic Learning, Department of Philosophy, Aarhus University, Denmark.
- Mattingly C. 1999. Narrative construction of the uncertain self. Presented at the Department of Psychology, Copenhagen University, Copenhagen, Denmark.
- Mattingly C. 1999. Narrative, occupation and the creation of hope. Presented at the Panel: Children's Occupations From Multiple Perspectives, American Occupational Therapy Association, Indianapolis, IN.
- Mattingly C. 1999. Narrative and the phenomenology of disability. Presented at the Danish School of Advanced Education for Occupational Therapists and Physiotherapists, Aarhus University, Denmark.
- Mattingly C. 1999. Narrative and self in medical anthropology. Presented at the Center for Health, Humanities and Culture, Aarhus University, Denmark.
- Mattingly C. 1999. Therapeutic plots and family dramas: The complexities of the collaboration between rehabilitation professionals and families in South Central Los Angeles. Presented at the Department of Philosophy, Aarhus University, Denmark.
- Mattingly C. 2000. Race and ethnicity in the clinical encounter. Presented at the Culture Brokering: Relating Health Care and Illness to Everyday Life, III Conferencia de Pesquisa Socio-Cultural, Sao Paulo, Brasil.
- Mattingly C, Fleming MH. 2000. Complex clinical reasoning in community-based care: The underground practice. Presented at the Annual Conference and Exposition of the American Occupational Therapy Association.



Early Cortisol Replacement to Prevent BPD: Pilot Study

Grantee

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Project Number MCJ-420633

NTIS Number PB2000-106931

Project Period 6/1/1996-5/31/1999

Costs	Direct Costs Awarded	Indirect Costs Awarded	Total
Year 1	97,912	51,218	149,130
Year 2	110,362	57,730	168,092
Year 3			
Year 4			
Year 5			

Year 2000 Objectives

14.1, 17.2

Study Design

Experimental

Time Design

Longitudinal

Care Emphasis

Interventional

Population Focus

Neonates

Race/Ethnic Focus

No Stated Race, Ethnic Focus

Summary

Statement of the Problem

Bronchopulmonary dysplasia (BPD), or chronic lung disease following neonatal lung injury, is a frequent complication of prematurity, and results in increased health care costs, prolonged hospital stays with frequent rehospitalizations, long-term pulmonary abnormalities, and subsequent compromise of growth and development. BPD is highly prevalent in very low birth weight infants (VLBW, <1500 grams birth weight), and is a leading cause of morbidity and mortality in this population. When defined as oxygen dependence at 28 days of life, the median reported incidence of BPD from 250 Newborn Intensive Care Units (NICUs) with total yearly admissions of more than 19,000 such infants was 48% of survivors (Vermont Oxford Annual Database Summary, 1997, Vermont Oxford Network, Burlington VT).

Because a very high percentage of extremely low birth weight infants (<1000g birth weight) remain on supplemental oxygen and even mechanical ventilation at one month of life, the term bronchopulmonary dysplasia applied to those infants at 28 days of life has lost much of its original connotation of severe disease. A new definition of chronic lung disease (CLD), as a continuing requirement for supplemental oxygen at 36 weeks postconceptional age, is increasingly reported, and may correlate better with adverse outcomes. This final report will therefore refer to chronic lung disease, or CLD, at 36 weeks postconceptional age, when discussing outcome. Using this definition, the Vermont Oxford database reports a median

incidence of 29% of all surviving VLBW infants. This incidence would translate to about 14,000 affected infants in the United States each year.

Therapies intended to reduce the incidence of CLD have thus far met with little success. For example, exogenous surfactant therapy for respiratory distress syndrome has significantly improved survival in VLBW infants, and decreased their exposure to high oxygen concentrations and high ventilator pressures; however, this therapy has not significantly decreased the incidence of CLD. Early use of high dose corticosteroid therapy, generally dexamethasone, has been reported to decrease the incidence of CLD, but with significant and worrisome systemic adverse effects, both short and long term. New therapeutic concepts are urgently needed to address this difficult clinical problem.

Research Questions or Hypotheses

Increased lung inflammation is a prominent and well-documented early feature of developing chronic lung disease. The reason or reasons that some infants develop this broad increase in markers of inflammation is not understood; however, we have also found that many of these infants show evidence of adrenal insufficiency early in life, and that such infants are more likely to develop CLD. We developed the following hypotheses:

1. Early adrenal insufficiency leads to exaggerated inflammatory responses and/or other abnormalities in lung function, leaving the small premature infant vulnerable to continuing lung injury, resulting in CLD.
2. Cortisol replacement therapy during the first 12 days of life will prevent this deficiency, thereby decreasing the incidence of CLD.
3. Cortisol replacement therapy during this time will also prevent symptoms of acute adrenal insufficiency, specifically hypotension, hyponatremia, hyperkalemia and delayed weight loss.

To provide a preliminary test of these hypotheses, and to provide the basis for designing a multicenter trial of cortisol replacement therapy in premature infants, we conducted a randomized, double blind, placebo-controlled pilot study, with the following research objectives:

1. To estimate the efficacy of cortisol replacement therapy during the first 12 days of life for prevention of CLD.
2. To estimate the effect of this cortisol replacement therapy on the signs of acute adrenal insufficiency listed above.
3. To evaluate the effects of such cortisol replacement therapy on adrenal hormone concentrations and on the ability of the adrenal gland to respond to ACTH.
4. To determine the effect of this replacement therapy on markers of inflammation in lung lavage fluid and peripheral blood leukocytes.

Study Design and Methods

This study was a randomized, double blind, placebo-controlled clinical trial including infants between 500 – 999 grams birth weight at two NICUs: the Children’s Hospital of Pennsylvania State University, Hershey, PA (June 1996 - May 1998) and Pennsylvania Hospital of the University of Pennsylvania, Philadelphia (June 1997 - May 1998). Infants were eligible if they were mechanically ventilated beyond 12 hours of life, could be enrolled before 48 hours of life, had no apparent major congenital anomaly or congenital sepsis, were considered appropriate for their gestational age, and had no history of maternal diabetes. Infants were enrolled after parental consent was obtained.

Patients received either placebo or hydrocortisone therapy for 12 days (1mg/kg/day for 9 days followed by 0.5mg/kg/day for 3 days). Blood samples were obtained at baseline, at day six and three days after the end of therapy (day of life 15 – 19). Response to ACTH stimulation was also determined at the last time point. Samples of tracheal fluid were obtained from intubated infants at study entry and on day four.

The primary outcome variable was ‘success’, defined as survival without chronic lung disease. Analysis of this primary outcome variable was by stepwise logistic regression, which included study center and other baseline population characteristics. Secondary endpoints included other measures of respiratory disease and clinical outcomes, and indicators of daily physiologic stability (e.g., fluid intake, enteral intake, blood pressure). Statistical tools included Student’s t test for population differences, Fisher’s exact test for adverse outcomes, multiple regression for continuous outcome variables, and area under the curve analysis for daily continuous data. Because chorioamnionitis is associated with increased cortisol concentrations, increased lung inflammation and adverse outcomes, we also examined this subset of patients separately.

Findings

Forty infants were enrolled (20 in each group); 17 in each group survived. Birth weight and gestation were similar for treatment (HC) and placebo groups (mean±SD: 732±135 grams (HC) versus 770±135 grams; 25.2±1.3 weeks (HC) v. 25.4±1.5 weeks).

Primary Objective: To evaluate the effect of this therapy on chronic lung disease. More infants treated with hydrocortisone achieved study success, defined as survival without CLD (12/20 (60%) versus 7/20 (35%); $p=0.023$; odds ratio 12.3, with 95% confidence limits of 1.8 – 151.5). The percentage of infants surviving without CLD in the placebo group (35%) was similar to that reported for this weight group by the Vermont Oxford Network (^a39%, extrapolated from 1997 report). Lower birth weight, chorioamnionitis and preeclampsia were significant risk factors in this regression, whereas study center, prenatal steroids, sex and ethnicity were not. Hydrocortisone therapy decreased days on >40% oxygen, days on >25% oxygen, days on mechanical ventilation, and oxygen at discharge. No significant differences were detected in adverse outcomes.

Objective 2: To evaluate effect on acute signs of adrenal insufficiency. During the treatment period, infants treated with hydrocortisone had significantly less hyponatremia ($p=0.004$) and showed a trend toward lower fluid requirements ($p=0.066$). Although the direction of effect for blood pressure and inotropic therapy (for hypotension) favored the treatment group, no significant differences were seen. These results were all consistent with the hypothesis that hydrocortisone replacement therapy would ameliorate signs of adrenal insufficiency. No significant difference was seen in the incidence of hyperkalemia, hypoglycemia or hyperglycemia. Because these infants were unstable and weighed infrequently, evaluation of early weight loss was not possible. Within the subset of infants exposed to chorioamnionitis, hydrocortisone treated patients received significantly more enteral nutrition during the first month of life ($p=0.01$), and weighed more at outcome (36 weeks postconceptional age, $p=0.03$).

Objective 3: To evaluate effect on adrenal hormone concentrations and response to ACTH stimulation. Analysis of cortisol concentrations showed that infants treated with hydrocortisone had no suppression of either basal or stimulated cortisol values when tested three days after the end of therapy. Additionally, hydrocortisone therapy had no significant effect on the concentrations of cortisol precursors 17OH pregnenolone, 17OH progesterone or 11deoxycortisol.

We then analyzed the differences in hormone concentrations between those infants who developed CLD and those who did not. We found that even at study entry, infants who developed CLD had significantly higher concentrations of 17OH progesterone, suggesting an impaired ability to synthesize cortisol, with accumulation of precursors. After the study (day 15 – 19), infants developing CLD had lower basal cortisol concentrations ($p=0.02$) and a reduced response to ACTH stimulation ($p=0.002$). In contrast, these infants continued to have significantly higher concentrations of 17OH progesterone, and increased ratios of precursor hormones (17OH progesterone and 11deoxycortisol) to cortisol, indicating a continuing limitation of ability to synthesize cortisol, resulting in accumulation of these precursors.

Objective 4: To determine effect on markers of inflammation in lung lavage fluid and peripheral blood leukocytes. Initial analyses have shown no significant differences between the treatment and placebo groups in these measures; however, the number of data points were few, especially considering the number of factors to be evaluated and the wide variability in the individual results. Therefore, the pilot study was too small to draw conclusions in this area.

Recommendations

In this study of early prophylaxis against adrenal insufficiency to prevent chronic lung disease in a population at high risk for both disorders, we found that hydrocortisone therapy significantly improved the likelihood of survival without CLD. The dose of hydrocortisone used in this study was equivalent to less than 10% of the dexamethasone dose currently used to treat CLD in these infants. This study was designed to evaluate potential benefit and calculate a sample size for a larger, multicenter trial. Although we saw no apparent increase in adverse outcomes, this study was not powerful enough to rule out a Type II error. This was a pilot study, and as such does not have the power to draw a negative conclusion. The results of this pilot study now justify a larger multicenter randomized trial to confirm the benefits and further assess the risks of low-dose hydrocortisone therapy to prevent chronic lung disease in extremely premature infants. If proven efficacious, this change in therapy would benefit thousands of infants not only by improving clinical outcomes, but also by avoiding the many adverse effects of currently practiced high-dose dexamethasone therapy.

Products To Date

Abstracts

Watterberg KL, Gerdes JS, Cook KL. 1999. Impaired glucocorticoid synthesis in preterm infants who develop chronic lung disease (CLD). *Pediatric Research* 45:232A.

Watterberg KL, Gerdes JS, Gifford KL. 1999. Treatment of early adrenal insufficiency to prevent chronic lung disease in preterm infants: Pilot study. *Clin Invest* 47:33A.

Watterberg KL, Gerdes JS, Gifford KL, Lin HM. 1999. Prophylaxis against early adrenal insufficiency to prevent chronic lung disease in premature infants. *Pediatric Research* 45:232A.

Articles

Watterberg KL, Gerdes JS, Gifford KL, Lin HM. 1999. Prophylaxis against early adrenal insufficiency to prevent chronic lung disease in premature infants. *Pediatric* 104(6):1258-1263.

Presentations

Watterberg KL. 1999. Protective strategies vs. cytokine-related pulmonary injury. Presented at the Cytokines in Perinatal Medicine, Perinatal and Developmental Medicine Symposium, Aspen, CO.

Watterberg KL. 2000. Early Cortisol Replacement to Prevent Bronchopulmonary Dysplasia: Pilot Study. Presented at the 31st



Growth and Development: Longitudinal Followup

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Project Number MCJ-240621

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Project Period 9/1/1992-8/31/1998

Costs	Direct Costs	Indirect Costs	Total
	Awarded	Awarded	
Year 1	142,893	66,967	209,860
Year 2	91,125	45,198	136,323
Year 3	99,899	44,955	144,854
Year 4	84,295	37,933	122,228
Year 5	97,422	43,300	140,722

Year 2000 Objectives

2.4, 7.4

Study Design

Experimental

Time Design

Longitudinal

Care Emphasis

Interventional

Population Focus

Preschool-aged Children, School-aged Children

Race/Ethnic Focus

African Americans

Summary

Statement of the Problem

Children who experience a deceleration in expected weight gain or fail to gain weight according to age and gender expectations are classified as having failure-to-thrive (FTT). FTT is usually related to inadequate nutritional intake. Although there are several severe medical conditions that can undermine children's growth (e.g., cystic fibrosis, HIV infection), in most cases of FTT, there are no clear medical explanatory factors. In contrast, psychosocial problems are common among families of children with FTT. Although FTT can be found in all segments of the population, it is more common among children from low income families. It is an early physical marker of risk because it provides clear evidence that a child is not achieving adequate growth. Thus, effective evaluation and management strategies require clinicians from multiple disciplines.

Little is known about the long term consequences of FTT because most of the research has been conducted among hospitalized children who may exhibit the most severe forms of FTT and there have been few follow-up studies. However,

the research that does exist suggests that children with FTT are at risk for growth deficits, decreased immunologic resistance, diminished physical activity, depressed performance in assessments of cognitive development, and poor academic performance. The relationship between nutritional status and consequences is often mediated by family, environmental, and cultural variables, making the family an ideal context for prevention of the negative consequences of FTT.

Research Questions or Hypotheses

This project was designed to evaluate the long term effects of home intervention on the growth and development of low income, inner-city children with non-organic failure to thrive (FTT) by building on an ongoing randomized clinical trial of home intervention. Children meeting growth criteria for FTT were recruited from a primary pediatric clinic when they were under two years of age and followed through 6 years of age. Of the 144 children with FTT recruited to the project, approximately half were randomized to receive home intervention for 12 months. Two comparison groups were recruited, matched by age, gender, and socioeconomic status (based on maternal education). The first group included 96 children of women at risk for HIV infection (most of whom were drug-abusing), recruited from a clinic for children of women at risk for HIV infection and the second group included 115 children with no identified problems (beyond low income), recruited from a primary pediatric clinic. This longitudinal project followed all children through their preschool years until they reached first grade. In keeping with the developmental-ecological theory guiding the research, attention was focused on the development of competence (defined through assessments of growth, cognitive development, and behavior); and children were studied in laboratory settings, in their homes, and in school. Multiple assessment strategies were used including direct observations, questionnaires, and standardized assessments. In addition to the evaluation of early home intervention and the relationship between indicators of growth and development, this longitudinal follow-up of low income, inner-city, minority children provides information on the protective factors that enable resilient children to have healthy growth and development despite overwhelming environmental challenges.

Study Design and Methods

The evaluation of home intervention among children with FTT was designed as a randomized controlled trial. The sample was stratified by age (1-8, 9-16, or 17-24 months), gender (male or female), and ethnic group (white or African American). A randomization procedure was used that yielded 12 lists -one for each possible combination of age, gender, and ethnic status. Families were assigned to intervention or control following their baseline assessment. Assignment was made by the community health nurse who supervised the home visitors. Intervention status was not included with the child's record. Therefore no members of the evaluation team were aware of the children's intervention status until the analysis was complete. All analyses comparing the intervention and non-intervention groups within the FTT sample were conducted using "intent to treat." That is children were placed in the intervention group if they were randomized to the intervention group, regardless of the amount of intervention received.

The three samples (FTT and two comparison groups) were recruited from primary care clinics at the University of Maryland Department of Pediatrics. Children were eligible for recruitment if they met the following criteria: gestational age greater than 36 weeks, birthweight appropriate for gestational age, no handicapping conditions, no congenital anomalies, and age under 25 months. All children in the FTT group had experienced a deceleration in growth defined as weight-for-age < 5th percentile, weight-for-height < 10th percentile, or crossing 2 major percentiles and all children in the HIV Risk group had mothers who were HIV positive or at risk for HIV, primarily due to drug use.

A major advantage of this sample is that the children were recruited from health care clinics, rather than from hospitalized settings. In the past much of the research on FTT has been biased because investigators relied on hospitalized samples. Yet, most children with FTT are treated as outpatients and are not hospitalized. Therefore much of the previous FTT research represented children with the most extreme medical and social profiles.

The analysis between children based on their initial risk status (FTT, HIV risk, and comparison) was designed as a cohort follow-up. With the exception of the children randomized into the home intervention component of the FTT group, none of the other children received intervention. Thus, we controlled for intervention status and compared the three groups of children.

Findings

Competence was defined using population-based measures of growth, cognitive performance, and behavior. Children had to achieve scores greater than one standard deviation below the mean (> -1 Z-score) to achieve competence. Thus, 84% of children would be expected to achieve competence on each measure. Only 35% of the children in the comparison group achieved competence in all three areas, suggesting the negative effects that poverty have on the development of competence among young children.

The findings reveal that most children with early FTT (prior to age 2) experienced growth recovery by age 6. Although they are thinner and shorter than comparison children, most are "on the curve" with height-for-age and weight-for-height greater than -1 Z-score (16th percentile). In addition, there do not seem to be lasting negative effects of FTT on children's cognitive performance or behavior at age 6 -they did not differ from children in the comparison group.

However, when FTT occurs in combination with other environmental risk factors (e.g., neglect), children do experience long-term negative outcomes. That is children who have a history of both FTT and neglect have worse scores on cognitive performance and several measures of behavior (home and school) than children who experience neither risk factor. This finding supports the cumulative risk theory.

When home intervention was considered among children in the FTT group, there were no direct effects of home intervention on children's competence at age 6, but there were moderating effects based on both child and maternal factors. Toddlers who received the intervention had highest rates of competence and children of mothers who were directive and received the intervention were more likely to achieve cognitive performance scores > 85 . Although modest, it is encouraging to find that the effects of a one-year intervention administered during infancy or toddlerhood were still evident at age 6.

Recommendations

Children who participated in the Growth and Nutrition Clinic experienced excellent improvements in growth. By age 6 only 3% of the children were stunted (length-for-age < 2 z-scores) or wasted (weight/height < 2 z-scores). These findings are consistent with other reports on the benefits of multidisciplinary clinics (Bithoney et al., 1987) and consistent with recommendations for current practice (Kessler & Dawson, 1999). Participation in the home intervention program did not influence children's growth, probably because all children were followed closely in the Growth and Nutrition Clinic and had frequent access to an interdisciplinary group of professionals, including a nutritionist, pediatrician, social worker, and psychologist. Thus, there did not appear to be a differential effect of the intervention on growth. These findings are consistent with findings from other investigations.

Overall the children experienced a decline in developmental status with increasing age that leveled off as they approached school age. However, toddlers who entered the program after the first year of life and received the intervention had better competence at age six than toddlers infants who did not receive the intervention. In addition, children of mothers who were directive during early feeding interactions and received the intervention had better scores on measures of cognitive performance at six than children of mothers who were not directive or did not receive the intervention. Because the effects of early intervention are moderated by maternal characteristics, interventions should be family-oriented, with additional attention directed to maternal mental health and parenting needs.

These findings reinforce the detrimental effects of poverty on children's competence. Not only was there a substantial decline in children's cognitive performance during the first six years of life, but only one-third of the children in the comparison group achieved overall competence on population-based measures of growth, cognitive performance, and behavior. Recent national data from Kids Count estimates that $> 20\%$ of American children are raised in poverty. Thus, millions of children raised in low-income families are at risk for negative outcomes.

There has been a great deal of rhetoric about the benefits of home intervention, especially theory-based, family-oriented, developmentally sensitive programs, such as the program implemented in this project. However, our findings are clear - there were no direct effects of home intervention on children's growth, cognitive development, or behavior. Rather there were moderated effects - that is the intervention was effective among subgroups of children - toddlers and children whose mothers had a directive parenting style. Thus, caution is warranted before adopting large scale home intervention programs. More research is needed to determine the conditions under which home intervention is most likely to be effective.

Products To Date

Articles

Bentley ME, Black MM and Hurtado E. 1996. Child feeding and appetite: What programs can do. *Food and Nutrition Bulletin* 16:340-348.

- Black M, Hutcheson J, Dubowitz H, Starr RH, Berenson-Howard J. 1996. The roots of competence: Mother-child interaction among low income, African American families. *Journal of Applied Developmental Psychology* 17:367-391.
- Black MM. 1999. Feeding problems: An ecological perspective. *Journal of Pediatric Psychology* 24(3):217-219.
- Black MM. 1995. Growth and nutrition clinic: Linking research and practice. *Child, Youth and Family Services Quarterly* 18(2):6-7.
- Black MM, Danseco ER, and Krishnkumar A. 1998. Understanding child health in a social context: A review of intervention research. *Children's Social Policy Research and Practice* 1:111-126.
- Black MM, Dubowitz H, Berenson-Howard J, Hutcheson J, Starr RH, Harrington D. 1995. Long-term follow-up of home intervention for children with failure-to-thrive. *Archives of Pediatrics and Adolescent Medicine* 149:56.
- Black MM, Dubowitz H, Starr RH Jr. 1999. African American fathers in low income, urban families: development, behavior, and home environment of their three-year-old children. *Child Development* 70(4):967-978.
- Black MM, Krishnakumar A. 1999. Predicting height and weight longitudinal growth curves of height and weight using ecological factors for children with and without early growth deficiency. *Journal of Nutrition* 129(2S Supplement):539S-543S.
- Black MM, Krishnakumar A. 1998. Children in low-income, urban settings. Interventions to promote mental health and well-being. *American Psychologist* 53(6):635-646.
- Dubowitz H, Black MM, Kerr MA, Starr RH, Harrington D. 2000. Fathers and child neglect. *Archives of Pediatrics and Adolescent Medicine* 154:135-141.
- Harrington D, Black MM, Dubowitz H, and Starr RN. 1998. Child neglect: A model of temperament and family context. *American Journal of Orthopsychiatry* 68:108-116.
- Hutcheson JJ, Black MM. 1996. Psychometric properties of the Parenting Stress Index in a sample of low-income African-American mothers of infants and toddlers. *Early Education and Development* 7:381-400.
- Hutcheson JJ, Black MM, Talley M, Dubowitz H, Berenson-Howard J, Starr RH and Thompson BS. 1997. Risk status and home intervention among children with failure to thrive: Follow up at age 4. *Journal of Pediatric Psychology* 22:651-688.
- Kerr MA, Black MM, Krishnakumar A. 2000. Failure-to-thrive, maltreatment and the behavior and development of 6-year-old children from low-income, urban families: a cumulative risk model. *Child Abuse and Neglect* 24(5):587-98.
- Mackner LM, Starr RH, Black MM. 1997. The cumulative effect of neglect and failure to thrive on cognitive functioning. *Child Abuse and Neglect* 21(7):691-700.
- Schuler M, Black M and Starr RH. 1995. Determinants of mother-infant interaction. The effects of prenatal drug exposure, social support and infant development. *Journal of Clinical Child Psychology* 24:397-405.

Chapters

- Black MM. 1998. Urban life and mental health. In H. Friedman, eds., *Encyclopedia of Mental Health* (Vol. 3, pp. 681-688). San Diego, CA: Academic Press.
- Black MM. 1999. Behavior problems in feeding. In PB Kessler, P Dawson eds., *Pediatric Undernutrition: Failure to Thrive in Young Children: A Transdisciplinary Approach* (pp. 151-172). Baltimore, MD: Paul H. Brookes Publishing Co.
- Black MM. 1999. Basic life skills to promote healthy nutrition patterns. In PB Kessler, P Dawson, eds., *Pediatric*

Undernutrition: Failure to Thrive in Young Children: A Transdisciplinary Approach (pp. 385-394). Baltimore, MD: Paul H. Brookes Publishing Co.

Black MM, Dansco ER. 1994. The impact of ecological theory on intervention research in maternal and child health. In *Proceedings of the Fourth National Title V Research Priorities Conference*.

Black MM, Dubowitz H. 1999. Child neglect: Research recommendation and future directions. In H Dubowitz, ed., *Child Neglect* (pp. 261-277). Newbury Park, CA: Sage Publications, Inc.

Dubowitz H, Black M. 1996. Medical neglect. In *The APSAC Handbook on Child Maltreatment*. Newbury Park, CA: Sage Publications, Inc.

Dissertations and Theses

Binder, A. 1995. Temperament and child neglect. Master's thesis, Department of Psychology, University of Maryland, Baltimore County, MD.

Busby S. 1999. Young children exposed to violence: Multilevel issues of contextual and protective factors. Master's thesis, Department of Psychology, University of Maryland, Baltimore County, MD.

Coulihan C. 1996. The impact of maternal depression, temperament on children's functioning: Neglect and failure-to-thrive. Master's thesis, Department of Psychology, University of Maryland, Baltimore County, MD.

Machner L. 1999. Cognitive development among children with and without failure to thrive. Doctoral dissertation, Department of Psychology, University of Maryland, Baltimore County, MD.

Mackner, L. 1996. The cumulative effects of neglect and failure-to-thrive on cognitive functioning. Master's thesis, Department of Psychology, University of Maryland, Baltimore County, MD.

Martinez, L. 1998. Neighborhood influences on children's development. Doctoral dissertation, Department of Psychology, University of Maryland, Baltimore County, MD.

McArdell N. 1995. Maternal psychological characteristics among parents of children with and without behavior problems. Master's thesis, Department of Psychology, University of Maryland, Baltimore County, MD.

Presentations

Bentley ME, Black MM. 1994. *Children's appetite and growth: Individual, maternal, and cultural influences*. Presented at the Federation of Associated Societies on Experimental Biology, Los Angeles, CA.

Bentley ME, Black MM, Hurtado E. 1994. *Child feeding and appetite*. What programs can do. Presented at the Cornell/UNICEF Colloquium on Care and Nutrition, Los Angeles, CA.

Black M. 1994. *Parent-child feeding partnership: Future challenges*. Presented at the Gerber Products Company, Fremont, MI.

Black M. 1995. *Who benefits from home intervention: Individual and ecological factors associated with success*. Presented at the Society for Research on Child Development Biennial Meeting, Indianapolis, IN.

Black M. 1995. *Home visiting: Lay workers can make a difference in children's health and development*. Presented at the Healthy Mothers, Healthy Babies Coalition, Arlington, VA.

Black M. 1995. *Evaluation strategies in early intervention programs and research*. Presented at the Healthy Mothers, Healthy Babies Coalition, Arlington, VA.

Black M. 1995. *Home visiting: A community based approach to children's health*. Presented at the Department of

Epidemiology Lecture Series, University of Maryland, Baltimore, MD.

Black M. 1996. *Resilience among 4 year old children of adolescent parents*. Presented at the Society of Adolescent Medicine, Washington, DC.

Black M. 1996. *Home intervention among infants with failure-to-thrive*. Presented at the National Center on Child Abuse and Neglect, Washington, DC.

Black M. 1996. *Infant development and nutritional status*. Presented at the Instituto de Investagacion Nutricional, Lima, Peru.

Black M. 1996. *Psychology's response to urban challenges: Interventions to promote mental health and well-being*. Presented at the American Psychological Association Presidential Mini Convention: A Tale of New Cities, Toronto, Canada.

Black M, Dubowitz H, Starr RH. 1996. *Father and child development*. Presented at the Center on Child Abuse and Neglect, Washington, DC.

Black M, Dubowitz H, Starr RH. 1996. *The role of fathers in at risk families*. Presented at the NICHD Family and Child Well-Being Network Conference on Father Involvement, Bethesda, MD.

Black M, Nitz K. 1995. *Growing up in low income urban communities: Parent-child interactions*. Presented at the American Psychological Association, New York, NY.

Black MM. 1995. *Home intervention among families of children with failure-to-thrive*. Presented at the Share Our Strength First National Conference, Washington, DC.

Black MM. 1995. *Precursors of neglect*. Presented at the Annual Meeting of the American Professional Society on the Abuse of Children, Tucson, AZ.

Black MM. 1997. *Lessons learned from home intervention*. Presented at the The Healthy Start/Healthy Beginnings Summit.

Black MM. 1998. *Home visiting: A strategy for prevention*. Presented at the American Psychological Association, San Francisco, CA.

Black MM, Dubowitz H, Starr RH. 1997. *Fatherhood and child development*. Presented at the San Diego Conference on Child Maltreatment, San Diego, CA.

Black MM, Hutcheson J, Talley M, Dubowitz H, Berenson-Howard J, Starr RH, Thompson BS. 1997. *Home intervention among children with failue to thrive: Outcome at age 4*. Presented at the San Diego Conference on Child Maltreatment, San Diego, CA.

Black MM, Krishnakumar A. 1998. *Predicting longitudinal growth among children with failure-to-thrive*. Presented at the Experimental Biology, San Francisco, CA.

Black MM, Krishnakumar A. 1998. *Longitudinal growth for children with early growth deficiency*. Presented at the Head Start's Fourth National Research Conference: Children and Families in an Era of Rapid Change, Washington, DC.

Black MM, Krishnakumar A. 1999. *Longitudinal growth of children with and without failure-to-thrive*. Presented at the Florida Child Health Psychology Conference, .

Dubowitz H, Black M, Provencano G. 1994. *Cost effects of home intervention*. Presented at the Ambulatory Pediatric Association, Seattle, WA.

Krishnakumar A, Black MM. 1998. *Estimating cognitive growth curves from enironmental risk factors: Mediating role of*

parents and child behaviors. Presented at the New Methods for the Analysis of Change Conference, Pennsylvania State University, Hershey, PA.

Krishnakumar A, Blackk M. 1999. *Child adaptability: A pathway to competence among low-income urban African American children from families with and without a history of drug use*. Presented at the Society for Research in Child Development, Al buquerque, NM.

Krishnakumar A, Kerr M, Dubowitz J, Black MM. 1998. *Maternal depression, hostility, and child behavior problems among victimized maternal caregivers: A longitudinal study*. Presented at the 126th Annual Meeting of the American Public Health Association, Washington, DC.

Mackner L, Black MM, Starr RH. 1999. *Cognitive development of children in poverty with adequate and deficient growth*. Presented at the Florida Child Health Psychology Conference.



Homeless Mothers and Children: Longitudinal Study

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Project Number MCJ-250809

NTIS Number PB99-158040

Project Period 12/1/1995-11/30/1997

Costs	Direct Costs	Indirect Costs	Total
	Awarded	Awarded	
Year 1	159,151	63,660	222,811
Year 2	59,781	23,852	83,633
Year 3			
Year 4			
Year 5			

Year 2000 Objectives

4.6, 6.3, 7.4, 7.5, 7.14, 8.3, 14.5, 14.11, 14.16, 17.2, 17.15, 20.11, 21.4

Study Design

Observational

Time Design

Mixed

Care Emphasis

Noninterventional

Population Focus

Infants, Toddlers, Preschool-aged Children, School-aged Children, Adolescents, Pregnant Women, Parents/Families/Mothers/Fathers (Adolescent Parents)

Race/Ethnic Focus

No Stated Race, Ethnic Focus

Summary

Statement of the Problem

Homelessness is a complex and tragic social problem. Various macro- and micro-economic forces affect the prevalence of homelessness in the general population and determine individual vulnerability. Although family homelessness has grown dramatically over the past 15 years, researchers know very little about the unique needs of this group. Previous research has been cross-sectional and has typically lacked comparison groups.

Research Questions or Hypotheses

The goal of this research project is to address these short coming and develop a better understanding of the course and consequence of family homelessness by following a cohort of homeless and low-income never homeless families over time. Specific goals include: 1) describing and comparing characteristics of sheltered homeless and low-income housed women and their children; 2) identifying risk and protective factors for family homelessness; 3) describing the natural course and consequences of family homelessness; and 4) examining the impact of homelessness and poverty on women and children.

The focus of the Maternal and Child Health Bureau Supplement was to increase enrollment so that we would have adequate power to explore issues related to maternal and child health, parenting, and the unique experiences of Puerto Rican women and children.

Study Design and Methods

The initial study used an unmatched case-control design to enroll 220 homeless families and 216 low-income, never homeless families in Worcester, Massachusetts. Homeless families were recruited from all 9 family shelters in Worcester. Housed families were recruited from public welfare offices, where these families were coming for a periodic redetermination of benefits. Mothers were enrolled into the study along with one child from each of three age groups, infants (4 months-2.5 years), preschoolers (2.5-6 years), and school-age (6 years or older). Mothers and children were assessed directly on such issues as socioeconomic characteristics, social support, violent victimization, life events, mental health, physical health, overall well-being, and service use. In addition to baseline assessments, families were re-interviewed at 12 month and 24 month intervals. Overall, mothers in the study were 27 years of age on average with two children in tow. The race/ethnic breakdown was 39% Non-Latino White, 17% African-American, 36% Latino (Puerto Rican descent), and 8% (other Latino). Mean annual income was \$7910 for homeless families and \$10,000 for housed families.

Population Description and Sampling Plan

Located in the central part of the state, Worcester is Massachusetts' second largest city, with a population of 169,000; fifteen percent of its residents live below the poverty line. As in many mid- and large-sized American cities, especially in the East and Midwest, the vast majority of homeless families in Massachusetts are headed by women. In Worcester, almost all families who become homeless go directly to a shelter as opposed to sleeping in a park, car, or abandoned building. Thus, we enrolled only female-headed families currently living in shelter, along with their dependent children under the age of 17. A comparison group of low-income mothers who had never been homeless was also selected.

Between August 1992 and July 1995, 220 homeless families were enrolled from all nine of Worcester's emergency shelters and transitional housing facilities, as well as from two welfare hotels (3.2% of the families). Study staff approached families who had been in shelter for at least seven days and asked mothers to participate in multi-session interviews. The majority (75%) of the 220 homeless families who we interviewed were new entrants into the shelter system having spent less than 18 weeks in shelter at the time of enrollment. For the majority of families (76.4%) this was their first homeless experience, while fifty-two women (23.6%) had been homeless on at least one occasion prior to their enrollment.

The comparison group of 216 families was enrolled from never homeless female-headed families who were receiving Aid to Families with Dependent Children (AFDC) and residing in public or private housing. Following epidemiologic principles, this comparison group was chosen to represent the base population from which cases emerge. Our intent was to select a comparison group of families who had never been homeless but were at economic risk for the condition. We did not match cases and controls, as the literature does not suggest risk factors for family homelessness (beyond poverty) that should be controlled through study design.

Project staff enrolled the comparison group by approaching women at the Worcester Department of Public Welfare (DPW) office. (We were not able to gain permission from DPW to construct a sampling frame). During the first third of the enrollment period, we recruited only women coming to DPW for redetermination of their benefits eligibility. To continue receiving benefits, a face-to-face appointment was required. These appointments were scheduled routinely, usually at six-month intervals. We were thus able to capitalize on an efficient process for randomly recruiting women on AFDC into our study. During the remainder of the comparison group's enrollment period, DPW policy changes lengthened the time between routine redetermination hearings, thereby reducing the flow of women. Therefore, we expanded recruitment to include women who came to DPW for other purposes. (Housed women who were enrolled after we changed the recruitment criteria were very similar to women previously enrolled).

Findings

Findings from the WFRP have been published in over 18 peer-review articles, and cover a range of topics. This research has documented a startling homogenization of homeless and housed families. Both groups are struggling with extreme financial deprivation, substandard living conditions, violent victimization, inadequate education, lack of job training and employment opportunities, social isolation, and poor physical and mental health. Experiences of violence are extremely high among

these women: 92% of the homeless and 82% of the housed mothers experienced severe physical and/or sexual assaults at some point in their lives. More than 40% in both groups were sexually molested as children. Not surprisingly, this exposure to violence appears to have resulted in serious emotional consequences for many women. More than one-third of women in the study had developed post-traumatic stress disorder (3 times the rate of the general female population) during their lifetimes and 16% currently met the diagnostic criteria for this disorder. Similarly, more than 40% of both homeless and housed women have had a major depressive disorder - a rate twice as high as in the general female population. Nearly one-third of homeless and housed women reported a current chronic health condition, with particularly high rates of asthma, anemia, and ulcers.

Among the key findings from the study's assessment of children was the strong association between a mother's mental health and her child's well-being. This relationship was observed in all three age groups, but was more pronounced in young children. This finding is particularly important given the high rates of interpersonal violence and related mental health problems in the study mothers.

Both homeless children and mothers face a range of chronic and acute health challenges. For children, homelessness is independently associated with fair/poor health status, higher symptom counts, higher rates of emergency room use, and more outpatient visits, controlling for background and health characteristics. Although homeless mother also had compromised health, they only differed from their housed counterpart in terms of higher rates of service use and more health risk behaviors.

In terms of cognitive development, and behavior in the children, homeless and housed infants and toddlers appear to be very similar. Homeless and housed preschoolers also appear to have similar cognitive functioning and similar rates of behavior problems. Among the school age children, cognitive functioning and mental health status was similar between the homeless and housed groups. Overall, these children had tremendously high rates of Axis-I diagnoses with functional impairment.

Recommendations

As a whole, the findings from the Worcester Family Research Project provide a comprehensive picture of the characteristics of homeless and housed low-income women and their children. The comparison of homeless and housed families revealed some striking differences and important similarities. Sheltered homeless mothers had fewer economic resources and social supports and higher cumulative rates of violent victimization over their life spans than their housed counterparts. In addition, homeless children have more adverse health outcomes.

The differences are overshadowed, however, by the extreme adversity faced by both groups. All of these families live well below the federal poverty level and have inadequate education, training, and employment opportunities. The astoundingly high rates of severe physical and sexual victimization and the high rates of adverse mental and physical health outcomes attest to the level of suffering experienced by both homeless and housed low-income families. Many of these families are extremely isolated and have few personal, community, or institutional supports.

Antipoverty programs now being reformed at the national, state and local levels should be based on sound scientific evidence. As the data suggest, the growing population of low-income families in the United States is already destabilized and in peril, even before the impending reductions. Rather than limiting and restricting scarce resources for benefits and support programs, mothers living in poverty need carefully targeted assistance that accounts for the realities of their lives. Programs for poor and homeless families must account for the relationship between a mother's well-being and her children's well-being. Additionally, programs for poor families should more aggressively acknowledge the extremely high rates of violent victimization. Children will likely experience negative consequences when their mothers safety and well-being are profoundly compromised. Effective programs should include violence screening for both mothers and children (including screening for witnessing violence in children), post-trauma treatment for mothers and children, violence prevention.

Our data suggest that the mental health needs of some children are not being attended to, either because of the lack of availability of services, barriers to treatment, or failure to recognize need. To understand better why some poor children lack critical services even when treatment is available, the realities of poor families' lives and barriers to service use must be considered. Single mothers, faced with the task of supporting and raising children with few social support and diminished economic aid, have many pressing and competing demands. It is important that the mother's stressors, including domestic violence and her current mental health status, be examined when devising a treatment plan. Family-based interventions are likely to be more effective in helping youths with mental health problems than are treatment plans that do not consider issues related to the mother, siblings, and extended family.

Community outreach to poor families that provides education about children's mental health problems and information concerning treatment efficacy is needed to promote service utilization. Providers' awareness of issues that a poor, single parent faces is vital in obtaining her involvement and cooperation in her child's treatment. Of course, mental health treatment needs to be affordable to poor families.

Finally, the issue of homelessness and poverty needs to be addressed with long-term solutions fulfilling low-income families needs for more affordable housing located in safe neighborhoods, opportunities for employment which pays a livable wage, decent available child care, adequate public transportation options, and access to affordable health and mental health care.

Products To Date

Articles

Bassuk EL, Buckner JC, Perloff JN, Bassuk SS. 1998. Prevalence of mental health and substance use disorders among homeless and low-income housed mothers. *American Journal of Psychiatry* 155(11):1561-1564.

Bassuk EL, Buckner JC, Weinreb LF, Browne A, Bassuk S, Dawson R, Perloff JN. 1997. Homelessness in female-headed families: Childhood and adult risk and protective factors. *American Journal of Public Health* 87(2):241-248.

Bassuk EL, Weinreb LF, Dawson R, Perloff JN, Buckner JC. 1997. Determinants of behavior in homeless and low-income housed preschool children. *Pediatric* 100(1):92-100.

Bassuk, et al. . (Summary heading - The characteristics and needs of sheltered homeless and low-income house mothers). *Journal of the American Medical Association* 276(8):640-646.

Coll CG, Buckner JC, Brooks MG, Weinreb LF, Bassuk EL. 1998. The developmental status and adaptive behavior of homeless and low-income housed infants and toddlers. *American Journal of Public Health* 88(9):1371-1374.

Weinreb L, Goldberg R, Bassuk E, Perloff J. 1998. Determinants of health and service use patterns in homeless and low-income housed children. *Pediatric* 102(3):554-562.

Weinreb L, Goldberg R, Perloff J. 1998. Health characteristics and medical service use patterns of sheltered homeless and low-income housed mothers. *Journal of General Internal Medicine* 13:389-397.



Improved Prenatal Detection of the Fragile X Mutation

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Project Number MCJ-360587

NTIS Number PB2000-106930

Project Period 9/1/1989-8/31/1999

Costs	Direct Costs	Indirect Costs	Total
	Awarded	Awarded	
Year 1	64,356	36,678	101,034
Year 2	60,700	38,603	99,303
Year 3	70,684	40,770	111,454
Year 4	74,079	42,538	116,617
Year 5	77,642	43,237	120,879

Year 2000 Objectives

14.3, 21.6

Study Design

Quasi Experimental

Time Design

Mixed

Care Emphasis

Noninterventional

Population Focus

Pregnant Women

Race/Ethnic Focus

No Stated Race, Ethnic Focus

Summary

Statement of the Problem

This project was initiated to improve the reliability of the prenatal detection of the fragile X chromosome, early on, and then the fragile X mutation, after the fragile X mental retardation-1 gene (FMR1) was cloned. During the earlier years of this project we improved fragile X chromosome cytogenetic detection prenatally by modifying the culture medium/system, demonstrated a continuing need for use of multiple fragile X induction systems, determined baseline levels of other fragile sites to serve as indicators for the chromosome induction system, improved fragile X mutation detection through application, where possible, of DNA linkage studies, tested the effectiveness of a putatively new cytogenetic test (and demonstrated that it was not what it was claimed to be), established SV40-transformed fragile X amniocyte and CVS lines to serve as controls in future studies, accounted for occurrence of a false negative result, showed that dialyzed fetal bovine serum was effective in fragile X detection, studied the occurrence of a common fragile site and related its impact to fragile X detection, showed that female fetuses with low fragile X chromosome frequencies could be detected reliably and showed that they have increased fragile X frequencies postnatally and were usually affected individuals, and applied direct DNA and PCR

testing to prenatal detection. We made significant progress in accomplishing our goal of improving fragile X chromosome detection and at the same time made a "seamless transition" to begin developing a molecular protocol for detection of the Fragile X mental retardation-1 gene (FMR-1) after it was cloned in the second half of 1991. By 1993, we had developed a protocol that was a combination of polymerase chain reaction (PCR) and Southern hybridization technology (Brown et al., 1993). At that time, we requested and obtained funds for competitive continuation of this project so that we could complete validation of the PCR/Southern analysis combination protocol and continue making improvements as well as disseminate important observations during the process of complete validation. Progress made during this past period is listed below. As mentioned in the 1993 critique of our request for competitive continuation, we believe that we have continued to "remain at the forefront of cytological [now becoming immunocytochemical rather than cytological, via our monoclonal antibody results] and molecular approaches for the detection of the Fragile X syndrome...[and our work has continued to provide] an important data base for occurrence of Fragile X..."

A list of articles/products is provided at the end of the detailed report as well as at the end of this executive summary section. We are grateful for the support of the Maternal and Child Health Program. With the support of the Maternal and Child Health Program, we were able to provide these investigative services (prenatal fragile X detection for women at increase risk) and new information now applied to our molecular combination protocol for improved prenatal fragile X prenatal detection, which has in its own way improved maternal and child health, would not have been possible. With the support of the Maternal and Child Health Bureau, our research program in prenatal fragile X detection has become a valuable national resource for not only prenatal fragile diagnosis but also research into ways to improve the test in an atmosphere of continuous change and breakthroughs in need of direct application to improved prenatal fragile X detection, improved maternal and child health. Our program has also provided a reference laboratory for start up laboratories around the country and the world and has also served as a repository of knowledge and experience for patients, physicians and scientists.

Research Questions or Hypotheses

1. To conduct studies for the improvement of the prenatal detection of the fragile X chromosome.
2. To develop and validate a molecular protocol for the prenatal molecular detection of the fragile X mutation.
3. To improve the polymerase chain reaction protocol for prenatal fragile X mutation detection, including reduced sample sizes and turnaround times.
4. To miniaturize the Southern analysis protocol, to reduce turnaround times and be able to utilize a specimens that otherwise were insufficient for analysis.
5. To conduct research toward the development/validation of monoclonal antibodies for the detection of the protein product prenatally in an effort to also reduce turnaround times for prenatal diagnosis.
6. To make use of any new information that becomes available via the literature for improved technology in prenatal fragile X mutation detection.

Study Design and Methods

In the first renewal application to continue this project from 1994-1999, continuation of the validation of the PCR technique for prenatal fragile X detection was proposed. This was accomplished by continuing to accept referrals from pregnant women who had been shown to be carriers of the fragile X premutation. Using the protocol that we had published at that time (Brown et al, 1993), specimens continued to be accepted for analysis from pregnant women known to be carriers of the FMR- 1 mutation. Our PCR prenatal protocol, then and now (but with some improvements, as will be mentioned), includes testing by direct DNA Southern blotting using probe StB12.3 as described in Brown et al (1993). It also included (but no longer necessary since about 1994 or 1995) cytogenetic testing as described by Jenkins et al (1992c). Over the next two years, results were reviewed and compared between molecular and cytogenetic protocols and there was good concordance between results of both protocol, such that cytogenetic testing was discontinued.

The PCR method for analysis of prenatal samples was improved through the investigation of various parameters including the method of DNA isolation, the cycle protocol, the study of ways to eliminate the use of detecting oligonucleotide probe. The use of a different gel apparatus allowed the sample to be concentrated in a much reduce area while minimizing the losses due to diffusion and distortion. Finally, research toward the development/application of a monoclonal antibody protocol for the identification of the gene product will be conducted on residual first and second trimester archived, and ultimately "fresh" specimens for the possibility of protein detection and absence and the diagnosis of the full mutation.

Findings

By studying ways to improve detection of the fragile X chromosome during the first five years of the project, we identified: an optimal culture medium, a combination or multiple fragile X induction system approach, fragile site controls. We also applied DNA linkage studies to the prenatal system where possible, tested a "new" cytogenetic test system, established amniotic fluid and chorionic villus transformed cultures, accounted for a false negative prenatal diagnostic result, demonstrated the use of dialyzed fetal bovine serum is effective in fragile site induction, determined the frequency of a common fragile site re. the potential for false positive diagnosis, demonstrated direct DNA prenatal detection of the FMR-1 mutation using Southern blotting, and were first to show the detection of the full mutation by PCR technology and also showed that low fragile X prenatal frequencies in females is a reliable indicator.

During the second five year period, we completed the validation of our molecular combination prenatal protocol, demonstrated that "CVS" is reliable for fragile X testing, studied the familial transmission of the FMR-1 C.G. repeat which ascertainment was facilitated through this project, demonstrated reverse mutations in female carriers, showed tissue difference in fragile X mosaics, suggested that low fragile X frequencies in CVS versus other cultures may be accounted for by several factors, provided new information on chromosome aneuploidy and fragile X syndrome, alerted the biomedical community to the phenomenon of "spontaneous fragile X chromosomes," miniaturized sample sizes and reduced turnaround times for both PCR and Southern analysis, effected sample size reduction by PCR modification of the Southern analysis, demonstrated the feasibility of FMRP detection at 10 weeks, distinguishing full mutations from controls including demonstrating, for the first time, this distinction in uncultured, squash preparations, and showing the feasibility of same day or next day result for at least full mutations using monoclonal antibodies.

Therefore, we have completed or made progress in all of the stated objectives.

Recommendations

Our combination molecular protocol for prenatal fragile X mutation detection, is being used in many laboratories nationally as well as world-wide. It should be recommended as the protocol of choice for prenatal detection of the fragile X mutation. Much useful information has been generated as a result of our endeavors in this area directly related to maternal and child health. We can now advise families regarding the size of the mutation being carried and estimate the empiric risks for expansion of the C.G. repeat in their fetuses should they plan their own families. One area in which these empiric risk estimates are poorly established is the gray zone (45 or 50-60 C.G. repeats) alleles. We plan to develop an assay based on characterizing AGG interspersions patterns within the C.G. repeats of women who carry alleles between 45 and 60 repeats, to better evaluate/estimate risks for expansion in this group of women. We are now in a position to study this situation in both male and female carriers, the results of which will be directly applied to providing better information for women carriers who are pregnant or are planning families.

We think that we have made significant contributions toward the improvement and establishment of prenatal fragile X testing technology, and we look forward to further improving, refining, and simplifying this technology so that larger segments of the public will be able to assess their risk for this extremely common genetic disorder.

As indicated in the Introduction, it is clear that we have made significant progress during the previous cycle and have established that our combined PCR and Southern analysis protocol (MCP) is validated and virtually 100% reliable (100% sensitive/specific) excluding maternal cell contamination, a problem intrinsic in any prenatal testing that relies on CVS and AF samples. Our combination protocol is really today's gold standard (we have been asked to set this protocol up or provide detailed methodology to laboratories across the country and in other parts of the world including Argentina, Canada, Columbia and Italy. But it still takes at times, up to 7 weeks for a final report to be issued due to the Southern analysis component of the MCP (Molecular Combination Protocol). Also, pregnant women with repeat sizes in the gray zone are in need of better risk estimate information which may become available through AGG interspersions analyses (AGG/IP).

Therefore additional studies include:

1' SSR/SA: Sample Size Reduction in the Southern analysis component of our MCP (molecular combination protocol).

Establishing our new protocol that significantly miniaturizes sample size relative to adapting PCR technology to Southern blot analysis component of our molecular combination protocol (PCP). This protocol could substitute completely for the Southern analysis portion of our present "gold standard" protocol (MCP). Or, it could serve as a complementary protocol to help when sample size is unavoidably small or the sample is received at a very late date to the extent that only this protocol will provide a timely answer. Only additional trials will determine this information.

2' SSR/PCR: Further reduction of sample size (and ultimate reduction in turnaround time, especially when Southern analysis is required) for the PCR part of our present protocol by adapting single cell technology to both CVS and amniocyte specimens. We have set it up in another laboratory for fragile X sperm typing and Lymphocyte analysis (not funded by the

MCH grant) and have just begun to attempt application to prenatal detection, and will continue as samples become sufficiently available in future referral of specimens and as personnel constraints are resolved (the technologist helping in the present prenatal fragile X (MCP) program is barely able to meet the demands of cell culture, PCR and mAb analyses.

3' mAb/FMRP: monoclonal antibody detection of FMRP in CVS and Amniotic fluid to further reduce turnaround time where detection of full mutations are concerned. As indicated in the above introduction/progress report, we have preliminary evidence, using monoclonal antibodies, that we have been able to distinguish full mutations from controls in cultured CVS and amniotic fluid cells, and we are now ready to begin running trials with direct samples. We hope to accumulate enough positive specimens over the next two to three years to establish this as a very rapid turnaround protocol for full mutation detection, perhaps able to obtain results within one day of sample receipt, as early as 10 weeks gestation. With the reduction in sample size necessary for prenatal fragile X detection, sufficient material should become available to standardize FMR detection directly rather than through cell cultures.

4' AGG/IP: Develop a protocol to analyze female gray zone alleles for their AGG interspersion patterns. A significant problem exists for women whose alleles fall within the so-called gray zone of deciding whether they are at risk for having affected or carrier offspring. This involves about 1 in every 50 women in the general population whose repeat allele is from 50-60 (the gray zone) or even 45-60. The risk for expansion to full mutation in their fetus seems to be related to interruption of the C.G. repeat by another triplet, AGG. When AGG interrupts the C.G. repeat, it stabilizes it, i.e., the C.G. repeat does not expand in the next generation. Although we have been able to determine AG interspersion patterns in male carriers, it has not yet been possible to do the same in females. However, we believe (see tests and measurements) that we are now in a position to develop approaches for the analysis of such gray zone alleles. AGG interspersion (AGG/IP) pattern analyses will result in the data that is critically needed to construct risk estimate tables for improved genetic counseling of pregnant and/or carrier women. Therefore, we propose to develop a protocol to analyze female carrier gray zone AGG interspersion patterns.

5' Application of new information/technology. We would also take advantage of any other new information that becomes available during the next five year cycle for appropriate application to our prenatal protocol thereby making any breakthrough immediately available to benefit pregnant women, a direct application to maternal and child health. For example we shall be following a novel protocol that utilizes PCR, rather than Southern analysis, to identify methylation in the full mutation. However, it is not yet applicable to prenatal analysis since it cannot be used to analyze females. The inactive [methylated] X chromosome exhibits amplification similar to that of a methylated FMR-1 mutation (Das et al., 1997/1998).

Products To Date

Abstracts

Brown WT, Goonewardena P, Ray J, Miezieski C, Krawczun M, Jenkins EC. 1991. Prenatally detected fragile X females: Counseling issues and long-term follow-ups. *American Journal of Human Genetics* 49:211.

Brown WT, Houck G, Jeziorowska A, Ding X, Dobkin C, Levinson FN, Sklower Brooks S, Jenkins EC. 1992. Development of a PCR protocol for fragile X carrier screening: Application to population screening and prenatal diagnosis (Abs. 68). *American Journal of Human Genetics* 51:A20.

Brown WT, Houck Jr, GE, Ding X, Dobkin C, Nolin S, Glicksman A, Sklower-Brooks S, Jenkins EC. 1994. Fragile X carrier screening and prenatal diagnosis by PCR. *Abstracts of the First Annual Meeting: Clinical Genetics and Clinical Laboratory Genetics, of the American College of Medical Genetics.*

Brown WT, Houck Jr, GE, Jeziorowska A, Levinson F, Ding X, Dobkin C, Zhong N, Henderson J, Sklower Brooks S, Jenkins EC. 1993. A rapid, non-radioactive fragile X PCR protocol: Application to carrier screening and prenatal diagnosis. *Abstracts of the Sixth International Workshop on the Fragile X and X-linked Mental Retardation.*

Brown WT, Nolin S, Houck G, Ding X, Glicksman A, Dobkin C, Jenkins E. 1995. Prenatal Diagnosis and carrier screening for fragile X. *Abstracts of the Seventh International Workshop on the Fragile X and Xlinked Mental Retardation.*

Brown WT, Nolin S, Houck G, Jr., Zhong N, Glicksman A, Ye L, Ding XL, Dobkin C, Jenkins E. 1995. Reverse mutations in fragile X syndrome. *Abstracts of the Seventh International Workshop on the Fragile X and Xlinked Mental Retardation.*

Brown WT, Nolin S, Houck Jr G, Ding X, Glicksman A, Li S-Y, Rabe A, Dumas R, Haubenstock H, Wen Y, Dobkin C, Jenkins F. 1997. Progress in diagnosis and understanding of the fragile X syndrome. *Abstracts of the International Conference on Mental Retardation: Genes, Brain & Behavior*.

Brown WT, Nolin S, Houck Jr GE, Glicksman A, Ding X, Li SY, Brophy P, Duncan C, Houck S, Dobkin C, Jenkins EC. 1996. Fragile X syndrome prenatal diagnosis. *Abstracts of the Third Joint Clinical Genetics Meeting: The 27th Annual March of Dimes Clinical Genetics Conference, Malformations and Syndromes - Developmental Mechanisms; and the Third Annual Meeting of the American College of Medical Genetics, Clinical and Laboratory Genetics*.

Brown WT, Nolin S, Houck Jr GE, Glicksman A, Ding X, Li SY, Brophy P, Brooks S, Dobkin C, Jenkins EC. 1996. Fragile X prenatal diagnosis by PCR and Southern blotting: Experience from the first 100 cases. *American Journal of Human Genetics* 59:A317.

Brown WT, Nolin S, Houck Jr GE, Zhong N, Glicksman A, Ye L, Ding X, Dobkin C, Jenkins EC. 1994. Reverse mutations in fragile X syndrome. *Abstracts of the Fourth International Fragile X Conference*.

Brown WT, Zhong N, Nolin SL, Houck GE, Jr, Glicksman A, Ding X, Cohen I, Sudhalter V, Dobkin C, Jenkins EC. 1995. Clinical-molecular correlations in Fragile X Syndrome: Role of mosaicism, AGG interruptions and founder effects. *Abstracts of the Second Joint Clinical Genetics Meeting: The 26th Annual March of Dimes Clinical Genetics Conference, Novel Approaches in the Treatment of Genetic Disorders; and the 2nd Annual Meeting of the American College of Medical Genetics, Clinical Genetics and Clinical Laboratory Genetics*.

Dobkin CS, Ding X, Li SY, Houck Jr GE, Nolin SL, Jenkins EC, Zhong N, Brown WT. 1996. Fragile X prenatal diagnosis by a novel Southern-PCR hybrid procedure. *American Journal of Human Genetics* 59:A320.

Dobkin CS, Nolin SL, Cohen I, Sudhalter V, Bialer MG, Ding XH, Jenkins EC, Zhong N, Brown WT. 1995. Differences between mosaicism in blood cells and skin fibroblasts suggest that skin may better predict brain function (Abs. 1953). *American Journal of Human Genetics* 57:A336.

Duncan CJ, Jenkins EC, Genovese M, Gu H, Schwartz-Richstein C, Lele KP, Krawczun MS. 1989. Internal controls for fra(X) induction systems: A suggestion (Abs. 385). *American Journal of Human Genetics* 45:A99.

Jenkins E, Brown W, Schonberg S, Krawczun M, Golbus M. 1991. Prenatal detection of fra(X)(q27.3) in female identical twins. *Abstracts of the Fifth International Fragile X Workshop*.

Jenkins E, Dobkin C, Ding X, Li SY, Houck GE, Jr., Brown T. 1995. Fragile X frequency levels correlate with size of the repeat expansion in lymphocyte, lymphoblastoid and clonal lymphoblastoid cultures from an unmethylated mosaic full mutation male individual. Abstracts of the Seventh International Workshop on the Fragile X and Xlinked Mental Retardation.

Jenkins E, Duncan C, Gu H, Genovese M, Krawczun MS. 1991. Dialyzed fetal bovine serum usually increases fra(X) expression. Abstracts of the Fifth International Fragile X Workshop.

Jenkins EC, Dobkin CS, Ding X, Li S-Y, Houck Jr, GE, Brown T. 1995. Threshold CGG repeat size for fragile site expression without methylation identified in lymphocyte, lymphoblastoid and clonal lymphoblastoid cultures from an FMR1 unmethylated mosaic full mutation individual. *American Journal of Human Genetics* 57:A117.

Jenkins EC, Duncan CJ, Gu H, Genovese M, Krawczun MS. 1991. The effect of dialyzed fetal bovine serum on fra(X) expression and mitotic index; the effect of folic acid on Fudr-induced fra(X) expression. *Cytogenetic Cell Genetics* 56:221.

Jenkins EC, Houck Jr G, Jeziorowska A, Ding X-H, Duncan CJ, Genovese M, Henderson J, Morys I, Stark-Houck S, Levinson F, Sklower Brooks S, Goonewardena P, Dobkin CS, Brown WT. 1992. Prenatal fragile X detection: Experience of 10 years including the introduction of molecular testing. *American Journal of Human Genetics* 51:A383.

Jenkins EC, Houck Jr GE, Ding X, Li S-Y, Stark-Houck SL, Salerno J, Genovese M, Glicksman A, Nolin SL, Zhong N, Sklower Brooks SL, Dobkin CS, Brown WT. 1995. Update on fragile X prenatal diagnosis: End of the cytogenetics testing era. Abstracts of the Second Joint Clinical Genetics Meeting: The 26th Annual March of Dimes Clinical Genetics Conference, Novel Approaches in the Treatment of Genetic Disorders; and the 2nd Annual Meeting of the American College of Medical Genetics, Clinical Genetics and Clinical Laboratory Genetics.

Jenkins EC, Krawczun MS, Duncan CJ, Stark SL, Kunaporn S, Schwartz-Richstein C, Gu H, Brown WT. 1989. Improved prenatal fra(X) detection: Explanation(s) for false negatives in chorionic villus and amniotic fluid cell cultures. *American Journal of Human Genetics* 45:A261.

Jenkins EC, Li S-Y, Gu H, Haubenstock H, Dumas R, Dobkin C, Brown WT. 1998. Is chromosome non- disjunction related to genetic background? *American Journal of Human Genetics* 63:A139.

Jenkins EC, Morys I, Henderson J, Genovese M, Carter M, Li SY, Houck Jr GE, Ding X, Stark-Houck SL, Dobkin CA, Brown WT. 1993. Fragile X induction systems in CVS cultures: Effect on cytogenetic, PCR, and direct DNA analyses of the FMR- 1 gene. Abstracts of the Sixth International Workshop on the Fragile X and X- linked Mental Retardation.

Jenkins EC, Morys I, Henderson J, Genovese M, Carter M, Li SY, Houck Jr, GE, Ding X, Stark-Houck SL, Dobkin CS, Brown WT. 1993. The effect of fragile X induction systems on cytogenetic, PCR and direct DNA analyses of the FMR-1 gene in CVS cultures. *American Journal of Human Genetics* 53:561.

Jenkins EC, Raguthu S, Adelman S, Gu H, Yao X-L, Houck Jr G, Ding X, Dobkin C, Wisniewski KE, Brown WT. 1996. Fragile X syndrome and sex chromosome aneuploidy: XYY mosaicism. Abstracts of the Third Joint Clinical Genetics Meeting: The 27th Annual March of Dimes Clinical Genetics Conference, Malformations and Syndromes - Developmental Mechanisms; and the Third Annual Meeting of the American College of Medical Genetics, Clinical and Laboratory Genetics.

Jenkins EC, Wen GY, Kim KS, Chen J, Li SY, Houck Jr GE, Ding X, Nolin SL, Dobkin CS, Brown WT. 1997. Feasibility of cytoplasmic and nuclear-specific monoclonal antibody prenatal CVS fragile X detection. Abstracts of the International Conference on Mental Retardation: Genes, Brain & Behavior.

Jenkins EC, Wen GY, Li SY, Houck GE, Jr., Ding X, Nolin S, Dobkin C, Brown WT. 1997. Studies of fragile X protein (FMRP) detection in cells from prenatal samples indicate variation in immunocytochemical staining intensities. Abstracts of the Fourth Joint Clinical Genetics Meeting: March of Dimes and American College of Medical Genetics.

Krawczun MS, Jenkins EC, Duncan CJ, Stark SL, Kunaporn S, Schwartz-Richstein C, Gu H. 1989. Distribution of autosomal fragile sites in prenatal fra(X). *American Journal of Human Genetics* 45:A263.

Krawczun MS, Jenkins EC, Stark-Houck SL, Duncan CJ, Ray, JH. 1990. Fra(X) prenatal diagnosis: Are endoreduplicated and tetraploid cells useful diagnostic criteria? *American Journal of Human Genetics* 47:A279.

Krawczun MS, Jenkins EC, Stark-Houck SL, Duncan CJ, Sanz MM, Ray JH. 1991. Is scoring of endoreduplicated and polyploid cells a useful diagnostic aid in prenatal fragile X diagnosis? Abstracts of the Fifth International Fragile X Workshop.

Levinson FN, Sklower Brooks S, Ding X-H, Houck Jr G, Jeziorowska A, Jenkins EC, Dobkin CS, Brown WT. 1992. Molecular carrier testing for fragile X syndrome during pregnancy. *American Journal of Human Genetics* 51:385.

Rengifo Lucero, Alegria A, Aguilar E, Nolin S, Jenkins E, Brown T. 1999. Analyses of FRAXA and FRAXE mutations by cytogenetic and molecular methods in a population with behavioral disorders in Colombia. *Abstracts of the Ninth International Workshop on Fragile X Syndrome and X-linked Disorders*.

Shapiro LR, Allitto B, Brown WT, Fenwick R, Jenkins EC, Nolin SL, Papenhausen P, Schwartz CE, Sugarman E. . Reduction in prevalence of the Fragile X Syndrome: Decrease in births. *American Journal of Human Genetics* 63:A241.

Sherman SL, Maddalena A, Howard-Peebles PN, Brown WT, Nolin S, Jenkins E, Schwartz C, Tarleton J, Shapiro LR,

Smits APT, van Oost BA, Youngs S, Jacobs PA, Martinez F, Barnicoat A, Hockey A, Staley L, Hagerman R, Kennerknecht I, Steinbach P, Barbi G, Filippi G, Grasso M, Taylor SAM, Robinson H, Webb T, Broome D, Dixon J, Ferreira P, Gustavson K-H, Meyer JL, Pai GS. 1993. Characteristic of the transmission of the FMR- I gene from pre- and full mutation carriers in a prospective sample of conceptuses. *Abstracts of the Sixth International Workshop on the Fragile X and X-linked Mental Retardation*.

Zhong N, Yang W, Houck GE, Ding X, Jenkins E, Dobkin C, Brown T. 1995. Identification of FRAXE mutations: A FRAXE microdeletion associated with a complex mosaic FRAXA mutation. *Abstracts of the Fifth International Fragile X Workshop*.

Zhong N, Ye LL, Ju W, Schupf N, Jenkins EC, Brown WT. 1997. Distribution of apolipoprotein E genotypes in the fragile X syndrome, Batten Disease, and Down syndrome populations. *Abstracts of the Fifth International Fragile X Workshop*.

Articles

Allingham-Hawkins DJ, Babul-Hirji R, Chitayat D, Holden JJA, Yang KT, Lee C, Hudson R, Wen GY, Jenkins EC, Goldberg EM, Genovese M, Brown WT, Wisniewski HM. 1999. Ultrastructure of the fragile X chromosome: New observations on the fragile site. *American Journal of Medical Genetics* 83(4):331-333.

Brown WT, Gross A, Goonewardena P, Ferrando C, Dobkin C, Jenkins EC. 1991. Linkage in fragile X families of three distal flanking markers: ST14, DX13, and F8. *American Journal of Medical Genetics* 38(2/3):343-346.

Brown WT, Gross A, Goonewardena P, Ferrando C, Dobkin C, Jenkins EC. 1991. Detection of fragile X non-penetrant males by DNA marker analysis. *American Journal of Medical Genetics* 38(2/3):292-297.

Brown WT, Jenkins EC, Goonewardena P, Miezjeski C, Atkin J, Devys D. 1992. Prenatally detected fragile X females: Long-term follow-up studies show high risk of mental impairment. *American Journal of Medical Genetics* 43(1/2):96-102.

Brown WT, Mouck Jr GE, Jeziorowska A, Levinson FN, Ding X, Dobkin C, Zhong N, Henderson J, Brooks SS, Jenkins EC. 1993. Rapid fragile X carrier screening and prenatal diagnosis using a nonradioactive PCR test. *Journal of the American Medical Association* 270(13):1569-1575.

Dobkin CS, Ding X, Li S-Y, Houck Jr G, Nolin SL, Zhong N, Jenkins EC, Brown WT. 1999. Accelerated fragile X prenatal diagnosis by PCR restriction fragment detection. *American Journal of Medical Genetics* 83(4):338-341.

Dobkin CS, Nolin SL, Cohen I, Sudhalter V, Bialer MG, Ding X-H, Jenkins EC, Zhong N, Brown WT. 1996. Tissue differences in fragile X mosaics: Mosaicism in blood cells may differ greatly in skin. *American Journal of Medical Genetics* 64:206-301.

Dobkin CS, Ding X-H, Jenkins EC, Krawczun NMS, Brown WT, Goonewardena P, Willner J, Benson C, Heitz D, Rousseau F. 1991. Prenatal diagnosis of fragile X syndrome. *Lancet* 338:957-958.

Erster,SKH, Brown WT, Goonewardena P, Dobkin CS, Jenkins EC, Pergolizzi RF. 1992. PCR analysis of fragile X mutations. *Human Genetics* 90(1/2):55-61.

Gorwill H, Nolin SL, Glicksman A, Jenkins EC, Brown WT, Howard-Peebles PN, Becchi C, Cummings E, Fallon L, Seitz S, Black SH, Vianna-Norgante AM, Costa SS, Otto PA, Mingroni-Netto RC, Murray A, Webb J, MacSwinney F, Dennis Cecconi A, Ricci U, Ricotti G, Biondi C, Scarselli B, Veri F. 1999. Fragile X premutation is a significant risk factor for premature ovarian failure: The International Collaborative POF in Fragile X Study - Preliminary Data. *American Journal of Medical Genetics* 83(4):322-325.

Hirst M, Knight S, Davies K, Cross G, Ocrati K, Raeburn S, Heeger S, Eunpu D, Jenkins EC, Lindenbaum. 1991. Prenatal diagnosis of fragile X syndrome. *Lancet* 338:956-957.

- Jenkins EC. 1989. Review of cytogenetic data for fragile x: prenatal samples.
- Jenkins EC, Brooks SE, Stark-Houck SL, Sklower Brooks SL, Brown WT. 1991. SV40-transformed fra(X) amniocytes. *American Journal of Medical Genetics* 38(2/3):464-466.
- Jenkins EC, Brown WT, Schonberg S, Krawczun MS, Goldberg J, Golbus MS. 1992. Prenatal detection of fra(X)(q27.3) in female identical twins: Reliability of low level cytogenetic prenatal expression in females. *American Journal of Medical Genetics* 43(1/2):128-135.
- Jenkins EC, Duncan CJ, Gu H, Genovese M, Krawczun MS. 1992. Dialyzed fetal bovine serum increases cytogenetic fragile X expression. *American Journal of Medical Genetics* 43(1/2):155-160.
- Jenkins EC, Duncan CJ, Sanz MM, Genovese M, Gu H, Schwartz-Richstein C, Lele K, Salandi ML, Krawczun M. 1990. Progress toward an internal control system for fra(X) induction by 5-fluorodeoxyuridine in whole blood cultures. *Pathobiology* 58:236-240.
- Jenkins EC, Houck Jr GE, Dig X-H, Li S-Y, Stark-Houck SL, Salerno J, Genovese M, Glicskman A, Nolin SL, Zhong N, Sklower Brooks SL, Dobkin CS, Brown WT. 1995. An update on fragile X prenatal diagnosis: End of the cytogenetic testing era. *Developmental Brain Dysfunction* 8:293-301.
- Jenkins EC, Krawczun MS, Stark-Houck SL, Duncan CJ, Kunapom S, Gu H, Schwartz-Richstein C, Howard-Peebles PN, Gross A, Brown WT. 1991. Improved reliability of prenatal fra(X)(q27.3): Prevention of false negatives in chorionic villus and amniotic fluid cell cultures. *American Journal of Medical Genetics* 38(2/3):447-452.
- Jenkins EC, Morys I, Henderson J, Genovese M, Carter M, Li S-Y, Houck Jr GE, Ding X, Stark-Houck SL, Dobkin CS, Brown WT. 1994. Fragile X induction systems in CVS cultures: Effect on cytogenetic, PCR, and genomic Southern blot DNA analyses of the FMR-1 gene. *American Journal of Medical Genetics* 51(40):436-442.
- Jenkins EC, Sanz MM, Ray JH, Stark-Houck SL, Brown WT. 1991. Distribution of diploidy, polyploidy and endoreduplication in fra(X) positive and negative lymphocytes, amniocytes and chorionic villi. *American Journal of Medical Genetics* 38(2/3):434-436.
- Jenkins EC, Wen GY, Kim KS, Zhong N, Sapienza VJ, Hong H, Chen J, Li S-Y, Houck Jr GE, Ding X, Nolin SL, Dobkin CS, Brown WT. 1999. Prenatal fragile X detection using cytoplasmic and nuclear-specific monoclonal antibodies. *American Journal of Medical Genetics* 83(4):342-346.
- Jenkins LS, Gruenert DC, Jenkins EC, Schonberg WA. 1991. Transformation and establishment of fragile-X cell lines from amniocytes. *American Journal of Medical Genetics* 38(2/3):416-417.
- Krawczun MS, Jenkins EC, Duncan CJ, Stark-Houck SL, Kunapom S, Schwartz-Richstein C, Gu H, Brown WT. 1991. Distribution of autosomal fragile sites in specimens cultured for prenatal fragile X diagnosis. *American Journal of Medical Genetics* 38(2/3):456-463.
- Nolin SL, Lewis FA, Ye LL, Houck Jr GE, Glicksman AE, Limprasert P, Li S-Y, Zhong N, Ashley AE, Feingold E, Sherman SL, Brown WT. 1996. Familial transmission of the FMR CGG repeat. *American Journal of Human Genetics* 59:1252-1261.
- Nolin SL, Snider DA, Jenkins EC, Dobkin CS, Patchell K, Krawczun M, Strong G, Colwell M, Victor A, Payyapilli T, Turczyn M, Little A, Nagaraja U, Doyule N, Kenefick B, Sullivan C. 1992. New York State Screening program for the fragile X syndrome: An update. *American Journal of Medical Genetics* 43(1/2):328-332.
- Nolin WL, Snider DA, Jenkins EC, Brown WT, Krawczun M, Stetka D, Dobkin CS, Strong G, Smith-Dobrinsky G, Victor A, Hughes K, Kimpton D, Little A, Nagaraja U. 1991. Fragile X screening program in New York State. *American Journal of Medical Genetics* 38(2/3):251-255.

Wen GY, Jenkins EC, Yao X-L, Yoon D, Brown WT, Wisniewski HM. 1997. Transmission electron microscopy of chromosomes by longitudinal section preparation: Application to fragile X chromosome analysis. *American Journal of Medical Genetics* 68:445-449.

Zhong N, Ju W, Brown WT, He LL, Jenkins EC, Schupf N. 1999. Distribution of apolipoprotein E genotypes in the Fragile X syndrome and Batten disease. *American Journal of Medical Genetics* 84:309-310.

Chapters

Brown WT and Jenkins EC. 1993. Fragile X Syndrome. In B Smith, G Adelman, eds., *Neuroscience Year*. Encyclopedia of Neuroscience (Supplement 3, pp. 53-55). Boston, MA: Birkhauser.

Brown WT and Jenkins EC. 1998. Fragile x syndrome. In G Adelman and BH Smith, eds., *Elsevier's Encyclopedia of Neuroscience* (2nd ed., CD-ROM). Boston, MA: Birkhauser.

Brown WT, Goonewardena P, Gross AC, Dobkin C, Jenkins EC. 1991. Molecular markers of fragile X: Application to males at risk in fragile X families. In Willey AM, Murphy PD, eds., *Fragile X/Cancer Genetics: Proceedings of the 1989 Albany Birth Defects Symposium XX. Progress in Clinical and Biological Research* (Vol. 368, pp. 73-78). May, NY: Wiley-Liss.

Brown WT, Houck G, Jeziorowska A, Ding X, Dobkin C, Levinson F, Sklower-Brooks S, Jenkins EC. 1992. Applications of molecular technology for clinical use in the Fragile X syndrome. In R Jenssen Hagerman, P McKenzie, eds., *1992 International Fragile X Conference Proceedings* (pp. 331-338). Dillon, CO: Spectra Publishing Co., Inc.

Brown WT, Houck G, Jeziorowska A, Ding X-H, Dobkin C, Zhong N, Levinson F, Sklower-Brooks S, Jenkins EC. 1993. Developing molecular technology for clinical use in the fragile X syndrome. In JA Holden and B Cameron, eds., *Proceedings of the First Canadian Fragile X Conference* (pp. 133-138). Kingston, Ontario:

Brown WT, Jenkins EC. 1989. Mental retardation, fragile X syndrome. In Adelman G, ed., *Encyclopedia of Neuroscience* (Supplement 1). Boston, MA: Birkhauser.

Jenkins EC, Brown WT. 1998. Prenatal diagnosis of the fragile X syndrome. In A Milunsky, ed., *Genetic Disorders and the Fetus: Diagnostic, Prevention and Treatment* (4th ed., pp. 314-331). Baltimore, MD: Johns Hopkins University Press.

Jenkins EC, Houck Jr GE, Jeziorowska A, Ding X-H, Duncan CJ, Genovese M, Henderson J, Morys I, Stark-Houck SL, Levinson F, Sklower Brooks SL, Goonewardena P, Dobkin CS, Brown WT. 1992. Prenatal detection of fragile X: Experience of 10 years including introduction of molecular testing. In R Jenssen Hageman and P McKenzie, eds., *1992 International Fragile X Conference Proceedings* (pp. 349-356). Dillon, CO: Spectra Publishing Co., Inc.

Jenkins EC, Krawczun MS, Brooks SE, Sklower Brooks SL, Shemman SL, Brown WT. 1991. Laboratory aspects of prenatal fragile X diagnosis. In Willey AM, Murphy PD, eds., *Fragile X/Cancer Genetics: Proceedings of the 1989 Albany Birth Defects Symposium XX. Progress in Clinical and Biological Research* (Vol. 368, pp. 27-42). May, NY: Wiley-Liss.

Jenkins EC, Shapiro LR, Brown WT. 1992. Prenatal diagnosis of the fragile X syndrome. In A Milunsky, ed., *Genetics Disorders of the Fetus* (3rd ed., pp. 241-255). Baltimore, MD: Johns Hopkins University Press.

Presentations

Brown WT. 1998. *Prenatal diagnosis and testing of for the fragile X syndrome*. Presented at the Diagnosis and Treatment of the Unborn Child, Tempe, AZ.

Brown WT, Nolin S, Houck Jr G, Ding X, Glicksman A, Li S-Y, Dobkin C, Jenkins E. 1997. *Progress in carrier screening and prenatal diagnosis of the fragile X syndrome*. Presented at the Eighth International Workshop on Fragile X

Syndrome & Xlinked Mental Retardation, Picton Ontario, Canada.

Brown WT, Nolin S, Jenkins E. 1996. *Results of 102 prospective prenatal studies of FMR1 by a combination of Southern and PCR analyses*. Presented at the Fifth International Fragile X Conference, Portland, OR.

Dobkin CS, Wilmont PL, Jenkins EC, Murphy PD. 1989. *Fragile X workshop I laboratory issues: Cytogenetic and DNA diagnostic testing*. Presented at the Birth Defects Symposium XX: Fragile X/Cancer Genetics, Albany, NY.



Injury Prevention in an Urban Pediatric Clinic

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Project Period 5/1/1994-4/30/1998

Costs	Direct Costs Awarded	Indirect Costs Awarded	Total
Year 1	143,714	95,237	238,951
Year 2	147,856	99,422	247,278
Year 3	193,203	130,698	323,901
Year 4	195,592	130,069	325,661
Year 5			

Year 2000 Objectives

9.1, 9.2, 9.4, 9.8, 9.21

Study Design

Experimental

Time Design

Longitudinal

Care Emphasis

Interventional

Population Focus

Neonates, Infants, Toddlers,
Parents/Families/Mothers/Fathers (Adolescent
Parents)

Race/Ethnic Focus

No Stated Race, Ethnic Focus

Summary

Statement of the Problem

It is widely known that injury is the leading cause of death for children in the United States and that children 0-4 years of age have especially high injury morbidity and mortality rates. A significant proportion of these injuries occur in and around the child's home. Such injuries have been found to disproportionately effect low-income and ethnic minority families. Pediatricians have been identified as key players in childhood injury prevention efforts but little is known about the extent and effectiveness of their counseling on parents' child proofing practices. Moreover, limited attention has been paid to better understanding the unique needs of low-income, inner city families when it comes to modifying the injury hazards in a home. Advances in understanding the unique needs of these families requires the study of improved pediatric counseling, an onsite resource center, and a home visit by injury prevention specialists. Enhanced anticipatory guidance is designed to heighten parents' perceptions about the risk and seriousness of injury and to help them overcome specific barriers to injury prevention that are associated with living conditions in the inner city. The onsite resource center developed through this study improves access to needed, low-cost safety supplies. The home visit intervention used in this study provides technical assistance for using and/or installing safety supplies. Findings from the evaluation of these interventions will have

important implications for the provision of injury prevention services in well-child clinics, especially those operating with limited resources and serving families living in impoverished urban areas.

Research Questions or Hypotheses

The overall aim of this research is to identify interventions that enhance parents' injury prevention practices with regard to fall, burn, and poisoning injuries to infants and toddlers. The study evaluates the extent to which clinic-based interventions of varying levels of resource intensity improve parents' injury prevention practices among a sample of economically disadvantaged families living in an urban area.

Study Design and Methods

The study design is a randomized controlled trial involving two cohorts of parents who were enrolled at a well-child visit when their infants are between 0-6 months of age and followed until 18 months of age. Cohort 1 (N=200) was randomized to receive standard care or enhanced anticipatory guidance. When cohort 1 follow up was complete, an onsite resource center opened and cohort 2 (N=200) was recruited. All cohort 2 parents received anticipatory guidance and access to the resource center; one-half of cohort 2 were randomly assigned to receive a home visit intervention, too. All parents were interviewed at enrollment and when their child was 12-15 months of age. In-home observations were used to confirm self-reported injury prevention practices.

The three interventions designed to impact parents' injury prevention practices included enhanced anticipatory guidance, a safety resource center, and home visits by community health workers. Each is described in more detail. The enhanced anticipatory guidance (EAG) included 5 hours of in-depth, experiential training in counseling for behavior change and injury prevention. It was provided in two evening sessions in faculty members' homes. Both the control (CG) and intervention (IG) groups in Cohort 1 received a single lunch time seminar on injury prevention presented by co-investigator, Dr. Wilson. Both the in-depth training and the seminar were based on the American Academy of Pediatrics TIPP recommendations and materials. The EAG training enhanced this material by emphasizing communication skills and focusing in more detail on six targeted safety behaviors (stair gates, no baby walkers, syrup of ipecac, locking poisons, safe hot water temperature, smoke alarms) through in-depth didactic material and interactive, "hands-on" demonstrations. All Cohort 2 residents received EAG training.

At the completion of Cohort 1, a safety resource center was established and all Cohort 2 residents and parents had access to it. The Children's Safety Center (CSC) was established with two overarching goals in mind: 1) to increase the accessibility and affordability of home safety supplies for low income families; and 2) to elevate the priority given to injury prevention in medical care settings. The notion is that just as families go to a pharmacy for medication, they should be able to go to a safety center where injury prevention products are available at a reasonable cost (given that unlike medications, there is no insurance coverage for safety supplies).

The CSC provides access to low-cost safety supplies, personalized education, and a home-like environment where safety devices can be demonstrated. The Center is staffed by a masters-level health educator who provides personalized education and demonstrations to visitors and safety training to professionals and the public. The CSC sells Syrup of Ipecac, cabinet latches, stair gates, smoke detectors and batteries, bath and candy thermometers, bicycle helmets and other safety supplies. The third and final intervention tested was home visits by community health workers for experimental patients in cohort 2. Community health workers (CHW) went to the family's home to assess injury hazards in the home and make recommendations about resolving them. The home visit took place after the child's 6 month well child visit and before he turned 9 months old.

Population Description and Sampling Plan

Parents (or the female caretaker) who brought their children to the primary care clinic were the target population for this study. The Harriet Lane Primary Care Clinic (HLPC) provides health supervision and acute care health services to 6300 children, 86% of whom receive Medicaid benefits or have no health insurance. The majority of patients cared for are African-American (82%) and live in the surrounding East Baltimore neighborhood, which is one of the most economically disadvantaged areas of the city. Nearly two-thirds of East Baltimore's adult population have not completed high school; one in three families lives below the Federal poverty level.

Any HLPC parent whose child was between 0-6 months of age and whose pediatrician was a first- or second-year resident was eligible to participate, unless in the pediatrician's judgement, the child had a significant clinical reason to be excluded

(e.g., severe developmental delay). Participants were recruited as they came into the HLPC for a scheduled or walk-in visit. Each participant was approached in the waiting room by the interviewer, who explained the study to the parent, completed the informed consent process, and conducted the baseline interview.

Findings

Results from Cohort 1. The sample for Cohort 1 included 31 first and second year pediatric residents who were randomly assigned to the intervention (n=18) or control group (n=13). From November 1995 to September 1996, a total of 196 parents of infants from birth to six months were enrolled (120 in the IG and 76 in the CG). The 18 IG physicians saw 117 patients (mean=6.5) for a total of 410 visits (mean=22.8), with a mean visit length of 26 minutes. The 13 CG physicians saw 73 patients (mean=5.6) for 281 visits (mean=21.6), with a mean visit length of 24 minutes. None of these differences between the IG and CG were significant by t-tests. Analysis of the audio taped visits found that IG physicians provided significantly more injury prevention counseling than CG physicians on five of six topics. IG visits compared to CG visits were significantly more likely to include counseling about: hot water (34% vs. 10%, $X^2 = 24.9$, $p=.0001$); smoke alarms (69% vs. 21%, $X^2 = 46.9$, $p=.001$); baby walkers (73% vs. 52%, $X^2 = 15.4$, $p=.001$); Syrup of Ipecac (44% vs. 12%, $X^2 = 22.9$, $p=.001$); and stair gates (50% vs. 37%, $X^2=8.5$, $p=.01$). Discussion of poison storage was similar between the two groups at 65%.

Of the enrolled sample, 88% (n=172) completed the follow up interview and 69% (n=136) completed the home observation.

Parent exit forms completed after each visit asked if the physician had helped with safety issues, scored 0 (no help) to 4 (great deal of help). Averaged over all visits, parents in the IG group rated their physician on average significantly higher than parents in the CG group (3.79 vs. 3.54, $t\text{-test} = 2.59$, $p=.01$). The home observation data indicated no statistically significant differences in safety behaviors between the two groups, both in an unadjusted analysis and after adjusting for exposure to the counseling and potential confounders. For two of the outcomes, differences were in the right direction, but did not reach statistical significance due to the small sample sizes (e.g., 59% in the IG vs. 50% in the CG had a working smoking detector; and 36% in the IG vs. 30% in the CG had stairs protected by a gate or door). These results suggest that physician training can increase injury prevention counseling and parents who receive additional counseling are more satisfied. The lack of effect on safety behaviors highlights the difficulty that low income, inner city families have complying with pediatric advice and underscores the need for additional interventions that reduce barriers and reinforce pediatric advice. To address these barriers, the second phase of the SAFE Home project included the development of a Children's Safety Center, as described in the next section.

Preliminary Results from Cohort 2. A total of 39 first and second year pediatric residents were enrolled in Cohort 2 and all received training in EAG. The Intervention Group (IG) included 20 randomly assigned residents, whose parents were offered a home visit in addition to use of the CSC. As described above, the home visitor helped families identify the hazards in their home and explained how to fix them, but was not able to actually install any safety devices due to liability concerns. The Control Group (CG) included 19 randomly assigned residents, whose parents were offered only the CSC. From November 1996 to March 1998, 87 families were enrolled in the IG and 91 families in the CG when their babies were 0-6 months old. Parents were followed until their babies were 12-15 months old, at which time a follow up interview was completed and a home observation scheduled. Before and after each visit, parents completed intake and exit forms, which included whether the parent had visited the CSC since her last visit and whether the physician had mentioned the CSC during the visit.

The 178 families enrolled in the study were followed for an average of 2.7 visits and 92% of the families said their physician talked to them about the CSC on at least one visit (60% said the physician talked about the CSC on two or more visits). Twenty-six percent (26%) of the enrolled families reported making at least one visit to the CSC. These rates did not vary between IG and CG status and indicate high levels of awareness of the CSC by both physicians and families, but relatively low rates of CSC utilization among the overall sample.

We were able to complete home observations on 122 (69%) of the enrolled sample; 55% of these families reported having visited the CSC at some time prior to the home observation and these rates that did not differ between IG and CG. There are two likely explanations for the difference in CSC utilization rates between the enrolled and completed samples. First, we may have retained more motivated families, which is a common experience in trials of other behavioral interventions.

Second, families may have visited the CSC between the time we completed data collection in the clinic and the time of the home observation, which could have occurred any time up to the child's second birthday. We are fortunate that we can address this question empirically in subsequent analyses. Data on psychosocial variables from the follow up interview will be used to address the first explanation, and data from records kept in the CSC will be used to address the second.

Nevertheless, the preliminary data from the home observations strongly suggest a positive effect of the CSC in comparisons between families who visited the CSC (n=67) and those who did not (n=54). CSC visitors compared to non-visitors were more likely to: have a stair gate if their homes had stairs (36% vs.17%, $X^2=4.3$, $p=.04$); keep poisons locked (15% vs. 6%, $X^2=2.9$, $p=.09$); and to have Syrup of Ipecac (48% vs. 6%, $X^2=30.0$, $p=.000$). CSC visitors compared to non-visitors were also less likely to have a baby walker (36% vs 42%), more likely to have a working smoking detector on every floor (56% vs. 54%), and to have all their stairs protected by gates or a door (30% vs. 19%), although these smaller differences were not statistically significant. There were no differences between IG and CG groups in their overall safety practices or in comparisons of CSC visitors and non-visitors within each group. Thus, these preliminary results suggest that families who visit the CSC have safer homes and that there is no added benefit of having a community health worker visit the home. If these results are confirmed in future analyses and studies, they have substantial implications for developing cost efficient home safety interventions because home visiting is considerably more resource intensive than building an on-site safety center.

A final consideration in building the case for the potential benefit of the CSC is a comparison of safety practices between Cohort 1 (before the CSC was built) and Cohort 2. Because these two cohorts were collected over a several year period, they may differ systematically in a number of ways, for example, in their exposure to safety related events other than the SAFE Home Project. Without drawing causal inferences, however, it is interesting to note that the rate of safety practices observed in Cohort 2 was higher than that observed in Cohort 1 for three of the six practices. In Cohort 2, 55% of the sample had a working smoke alarm on every floor, whereas in Cohort 1, only 22% did so. Similarly, 11% of Cohort 2 compared to 6% of Cohort 1 kept any poisons locked; 29% of Cohort 2 and 10% of Cohort 1 had Syrup of Ipecac. It is possible that the widespread exposure to the CSC in Cohort 2 (98% of families reported their physician mentioned the CSC) helped stimulate increased attention to safety among all patients who took action to obtain needed safety supplies either through the CSC or elsewhere.

Recommendations

Analyses are still underway. Recommendations are pending completion of final data analysis. In the meantime, indications are that improving access to safety supplies helps parents comply with pediatric advice.

Products To Date

Articles

Gielen AC, McDonald EM, Forrest CB, Harvilchuck JD, Wissow L. 1997. Injury prevention counseling in an urban pediatric clinic. *Archives of Pediatrics and Adolescent Medicine* 151(2):146-151.

Gielen AC, Wilson ME, McDonald EM, Serwint JR, Andrews JS, Hwang WT, Wang MC. 2001. Randomized trial of enhanced anticipatory guidance for injury prevention. *Archives of Pediatrics and Adolescent Medicine* 155(1):42-49.

Chapters

Gielen AC, McDonald EM. 1996. PRECEDE/PROCEED. In K Glanz, FM Lewis, BK Rimer, eds., *Health Behavior and Health Education: Theory, Research, and Practice* (2nd ed.). San Francisco, CA: Jossey-Bass Publishers.

Presentations

Gielen AC. 1996. *Injury prevention in an urban pediatric clinic, and the Safe Communities/Baltimore project*. Presented at the Maryland Injury Prevention Network Meeting, Baltimore, MD.

Gielen AC. 1997. *Behavior change and injury prevention*. Presented at the World Bank, College Park, MD.

Gielen AC. 1997. *Translating principles into practice*. Presented at the National Youth Leadership Forums on Medicine, Injury Prevention, Washington, DC.

- Gielen AC. 1998. *Injury prevention counseling techniques*. Presented at the Pediatric Trends Annual Meeting, Baltimore, MD.
- Gielen AC. 1998. *Integrating perspectives on prevention of unintentional injuries*. Presented at the Public Health in the 21st Century, Behavioral and Social Science Contributions, Atlanta, GA.
- Gielen AC. 1998. *Behavioral sciences and the prevention of unintentional injuries*. Presented at the Public Health in the 21st Century, Behavioral and Social Science Contributions, Atlanta, GA.
- Gielen AC, McDonald E, Forrest C, Harvilchuck J, Wissow L. 1996. *Injury prevention counseling in an urban pediatric clinic*. Presented at the Third International Conference on Injury Prevention and Control, Melbourne, Australia.
- Gielen AC, McDonald EM. 1995. *The impact of household injuries: Practical solutions*. Presented at the Healthy Mothers, Healthy Babies Annual Conference, Baltimore, MD.
- Gielen AC, McDonald EM. 1996. *Childhood safety and injury prevention*. Presented at the Mayor's Eighth Annual Child Care Conference, Baltimore, MD.
- Gielen AC, McDonald EM. 1996. *Protecting our children: Issues in childhood injury prevention*. Presented at the National Association of Governor's Highway Safety Representatives (NAGHSR) Annual Meeting, Nashville, TN.
- Gielen AC, McDonald EM, Wilson M, Andrews J, Serwint JR, Chen LH, Hwang WT, Wang MC. 1998. *Evaluation of a clinic-based injury prevention program for inner-city families*. Presented at the Fourth World Conference on Injury Prevention, Amsterdam, Netherlands.
- Gielen AC, McDonald EM, Wilson MEH, Serwint JR, Andrews J, Alkire. 1999. *Reducing child injury risk by improving parents' access to home safety products*. Presented at the Seventh International Conference on Product Safety Research, Bethesda, MD.
- Gielen AC, McDonald EM, Wilson MEH, Serwint JR, Andrews J, Hwang WT, Wang MC. 2000. *Safer homes through improved access to safety supplies: Evaluation of a hospital-based children's safety center*. Presented at the Fifth World Conference on Injury Prevention, New Delhi, India.
- Gielen AC, Wilson M, McDonald EM, Andrews J, Serwint J. 1999. *Behavioral science theory applied to injury control: A case study of child safety*. Presented at the Third National Conference on Injury Prevention and Control, Brisbane, Australia.
- McDonald Em, Gielen AC. 1999. *Experimental training to improve pediatric counseling about injury prevention*. Presented at the Mid-Year Meeting of the Society for Public Health Education, Little Rock, AR.
- McDonald EM, Gielen AC, Alkire JE, Serwint JR, Andrews J, Wilson MEH. 2000. *An innovative service to prevent injuries to children*. Presented at the National Congress on Childhood Emergencies, Baltimore, MD.
- McDonald EM, Gielen AC, Hwang WT, Wilson MEH, Serwint JR, Andrews J, Wang MC. 2000. *Promoting child safety: How to get parents to buy it*. Presented at the Fifth World Conference on Injury Prevention and Control, New Delhi, India.
- McDonald EM, Gielen AC, Serwint JR, Andrews J, Wilson M. 1996. *SAFE Home Project: Injury prevention in an urban pediatric clinic*. Presented at the 124th Annual Meeting of the American Public Health Association, New York, NY.
- McDonald EM, Gielen AC, Serwint JR, Andrews J, Wilson M. 1997. *A program to enhance home safety for infants and toddlers*. Presented at the Safe America: Fourth National Injury Control Conference, Washington, DC.
- McDonald EM, Gielen AC, Wang MC, Serwint JR, Andrews J. 1998. *Assessing exposure to an intervention with self-report and audiotapes of medical encounters*. Presented at the Fourth World Conference on Injury Prevention, Amsterdam, Netherlands.

Wilson M, Gielen AC, Andrews J. 1998. *Anticipatory guidance for child injury prevention: Practical approaches*. Presented at the Annual Meeting of the Pediatric Academic Society, New Orleans, LA.



Marital Conflict and Adolescent Risk Behaviors

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Project Number MCJ-060623

NTIS Number PB2000-106923

Project Period 10/1/1992-3/31/1997

Costs	Direct Costs Awarded	Indirect Costs Awarded	Total
Year 1	214,370	92,179	317,021
Year 2	62,735	28,231	318,522
Year 3			306,549
Year 4			90,966
Year 5			

Year 2000 Objectives

3.5, 3.9, 4.5, 4.6, 4.8, 5.4*, 5.5, 5.6, 6.13, 6.14, 18.3*, 18.4*, 19.9*, 19.10*, 22.4

Study Design

Observational

Time Design

Longitudinal

Care Emphasis

Noninterventional

Population Focus

Adolescents, Parents/Families/Mothers/Fathers
(Adolescent Parents)

Race/Ethnic Focus

Hispanics-Mexican Americans

Summary

Statement of the Problem

Numerous studies have shown that interparental conflict is related to children's adjustment. However, most studies examining parental conflict and child adjustment have focused on European American children. Latinos are a large and increasing ethnic group in the United States, and nearly two-thirds of Latinos are Mexican American. Nonetheless, no studies to date have assessed the impact of interparental conflict on the adjustment of Latino children in general or Mexican American children in particular. Because values regarding family and personal relationships in Mexican American and European American culture appear to differ in several respects, Mexican American and European American children may have distinct responses to their parents' conflict.

Health risk behaviors are major causes of morbidity and mortality among adolescents, but the influence of parental conflict on health risk behaviors among adolescents has seldom been examined. Moreover, little is known about the process by which interparental conflict might influence child or adolescent adjustment. Recently, several investigators have suggested that children's cognitive and emotional responses to parental conflict are critical mediating processes. Children may appraise their parents' conflict for threat to themselves, experience emotional distress if they appraise the conflict as threatening, and engage in coping strategies that may or may not be successful in reducing emotional distress. Children's exposure to

frequent, intense, child-related, and unresolved interparental conflict may result in chronic emotional arousal and inability to regulate emotions and behavior. These emotional reactions may lead to adjustment problems. A final issue is that most studies of interparental conflict have assessed a single dimension of conflict, or have utilized a global measure. Six dimensions of parental conflict have been identified as potentially influencing child adjustment. These are frequency of conflict, child-related content, intensity of conflict, parental behavior during the conflict, child involvement in their parents' conflict, and the degree of conflict resolution.

Research Questions or Hypotheses

This study had four major goals:

1. To develop a multidimensional measure of interparental conflict that would be appropriate for use with both parents and adolescents and with Mexican Americans and European Americans.
2. To examine the effects of interparental conflict on health risk behaviors among young adolescents in intact families.
3. To include in the research families that were either Mexican American or European American, and to test all hypotheses separately for these two groups. This would allow distinct patterns of relationships to emerge within each cultural group.
4. To test a theoretical model to explain how interparental conflict might influence risk behaviors among adolescents. We hypothesized that adolescents' appraisal and emotional distress would mediate the relations between interparental conflict and adolescents' health risk behaviors. Specifically, we expected greater parental conflict to increase adolescents' appraisal of the conflict as threatening. We further expected that adolescents' negative appraisal regarding the conflict would be related to heightened emotional distress, including anxiety, depression, and anger. Finally, we hypothesized that more emotionally distressed adolescents would engage in higher levels of risk behaviors, including substance use and sexual activity.

Study Design and Methods

In the study development phase, we conducted focus groups to generate items for the dimensions of interparental conflict. We translated, back-translated, and decentered the entire interview. We pretested the interview by verbally administering it and revising it repeatedly until all items performed adequately.

We developed the Multidimensional Assessment of Interparental Conflict (MAIC), which assesses six dimensions: frequency, child-related content, intensity, parental behavior during conflict, child involvement, and resolution. Parental behavior during conflict includes four subdimensions for each parent's behavior: demand, dominate, withdraw, and express feelings. We developed parallel forms of the MAIC for parents and adolescents.

A total of 304 adolescents, ages 12-15 years, and their parents participated in the research. Of these, 153 families were Mexican American and 151 were European American. Participants were randomly selected from the membership lists of a large health maintenance organization. Altogether, 74% of eligible families participated in the research. Each participant was interviewed individually face-to-face at an initial baseline interview. At 6- and 12-month follow-up interviews, each participant was interviewed individually by telephone. Interviews with Mexican Americans were conducted by bilingual, bicultural interviewers in the language preferred by participants. The attrition rate over the entire study period was less than 2%.

In baseline interviews, parents reported on their marital conflict, their marital satisfaction, and they completed a measure of social desirability. At baseline, adolescents reported on their parents' conflict, their own appraisals about the conflict, their current emotional distress, and their self-perceptions. In baseline and follow-up interviews, adolescents responded to questions about their substance use and sexual behavior.

Findings

To determine which items should be included in each theoretically-derived scale, we conducted exploratory factor analyses followed by confirmatory factor analyses. Most of the scales showed acceptable fit in the confirmatory factor analyses (86%). For both ethnic groups, the same items loaded on each scale. Internal consistency of the scales, using Cronbach's alpha, was generally good, ranging from .61 to .89 for the European Americans, and .53 to .86 for the Mexican Americans. Most conflict dimensions had low to moderate correlations with each other, indicating that they were statistically as well as conceptually independent from one another. The most notable exceptions were father demand and dominate, and mother demand and dominate, which were highly correlated for both ethnic groups ($r = .49-.63$). In general, family members

showed moderate agreement with one another on the interparental conflict dimensions. Correlations with other measures indicated that the validity of the parental conflict scales was good. All but one dimension of interparental conflict were significantly associated with marital satisfaction. About half of the dimensions of conflict had low but significant correlations with social desirability. For adolescent ratings of parental conflict, each conflict dimension was related to one or more self-perceptions of scholastic competence, behavioral conduct, and global self-worth. We had hypothesized that interparental conflict would be related to adolescents' health risk behaviors. For Mexican American adolescents, more child-related content, mothers being more demanding/dominating during conflict, children being more involved in the conflict, and children perceiving that the conflict was less resolved were related to several risk behaviors. For European American adolescents, more child-related content, fathers being more demanding/dominating during conflict, fathers withdrawing during conflict, both fathers and mothers expressing more feelings during conflict, and children perceiving that the conflict was less resolved were related to risk behaviors. Our test of the theoretical model revealed that for both ethnic groups, adolescents' appraisal of the conflict was not a good mediator of the relations between parental conflict and adolescents' risk behaviors. Instead, adolescents' perceived conflict resolution and emotional distress mediated the relations between some dimensions of interparental conflict and risk behaviors. For Mexican American adolescents, more child-related content and mothers' greater demanding/dominating behavior during conflict were related to adolescents' perceptions that conflict was less resolved. For European American adolescents, fathers' being more demanding/dominating behavior during conflict and fathers' withdrawing more during conflict were related to adolescents' perceptions that conflict was less resolved. Adolescents who perceived their parents' conflict to be less satisfactorily resolved also reported more emotional distress, including depression, anxiety and anger. Finally, adolescents who were more emotionally distressed engaged in more alcohol use, tobacco use (European Americans only), marijuana use (Mexican Americans only), and sexual behavior.

Recommendations

We developed the Multidimensional Assessment of Interparental Conflict (MAIC), a measure that can be completed by parents and adolescents. The measure is appropriate for use with both Mexican Americans and European Americans, and analyses conducted thus far indicate that it has good reliability and validity. Our results show that measuring interparental conflict multidimensionally is more informative than using a global measure. Certain dimensions of interparental conflict were related to adolescents' emotional distress and health risk behaviors. Some dimensions of parental conflict were important for both ethnic groups, and some were important for only one group. We suggest that future studies investigating the effects of interparental conflict on child adjustment measure multiple dimensions of conflict, particularly child-related content, child involvement in the conflict, parental behavior during conflict, and children's perceptions of conflict resolution. Although our results for Mexican Americans and European Americans shared similarities, some of our findings were distinct for each ethnicity. Because a given behavior may have different meanings across cultural groups, we suggest that research on family relationships and child adjustment will provide more interpretable results if processes are examined within each group, as we did in this research, rather than compared across ethnic groups. A related issue is that interpretation of results within a given cultural group can be facilitated by measuring cultural values directly. Further, measurement of key cultural values would provide more information about protective and vulnerability processes within that group. For both Mexican American and European American adolescents, several dimensions of interparental conflict were related to higher levels of substance use and sexual experience. Further, for both groups, adolescents' perceptions of their parents' conflict resolution and their own emotional distress mediated the relations between some dimensions of parental conflict and adolescents' risk behaviors. Based on these results, we suggest that several types of prevention programs would be useful. In-service training programs for health care providers could emphasize the link between parental conflict and the development of health risk behaviors among young adolescents. Providers could use screening questions to determine which adolescents or families should be referred to counseling or therapy. Prevention programs could also be targeted to parents, perhaps as classes offered by HMOs. Primary prevention programs could focus on identifying destructive aspects of parental conflict and helping parents to understand adolescents' perceptions of parental conflict, how this affects adolescents emotionally, and how adolescents cope with family stress. Programs should include communication skills training and problem-solving training, and be tailored to specific cultural groups, so that cultural values shared by a given group could be incorporated into the program. Third, prevention programs for adolescents could be offered in school settings as part of existing substance use prevention and sex education programs. Such programs should discuss how adolescents may become involved in health risk behaviors partially because of family factors such as parental conflict, and how adolescents often experience emotional distress resulting from their parents' conflict. Programs should focus on identifying negative feelings and developing effective coping skills to reduce emotional distress.

Products To Date

Articles

Tschann JM, Flores E, Pasch LA, Marin BV. 1999. Assessing interparental conflict: Reports of parents and adolescents in European American and Mexican American families. *Journal of Marriage and the Family* 61:269-283.

Presentations

Casey-Cannon S, Pasch, LA, Tschann, JM, Flores E. 1998. *The effects of family environment and supportive non-parent adults on adolescents*. Presented at the Society for Research on Adolescence, San Diego, CA.

Tschann, J.M., Flores, E., Pasch, L.A., & Marin, B.V. 1999. *Interparental conflict and adolescent health risk behaviors in Mexican American families*. Presented at the Society for Research in Child Development, Albuquerque, NM.

Tschann JM, Flores E. 1995. *Parental marital conflict and adolescents' responses: A multidimensional approach*. Presented at the American Psychological Association, New York, NY.

Tschann JM, Flores E, Marin BV. 1996. *Parental marital conflict and adolescent health risk behaviors*. Presented at the Society for Research on Adolescence, Boston, MA.

Tschann JM, Flores E, Marin BV . 1997. *Parental marital conflict and adolescent risk behaviors: A cognitive-emotional model*. Presented at the Society for Research in Child Development,, Washington, DC.

Tschann JM, Marin BV, Flores E. 1995. *Young adolescents' responses to parental marital conflict: A multidimensional perspective*. Presented at the Society for Research in Child Development, Indianapolis, IN.

and assessment.

Research Questions or Hypotheses

As ultimately conducted, the project had six aims.

1. To contribute to the methodology of the field by testing existing assessment instruments, created for abusive families, to ascertain their sensitivity to a preventive intervention. In addition, to create new measures where few or none exist to specifically assess the domains relevant to our conceptual model and to be sensitive to a preventive intervention. The conceptual model will be discussed in some detail later in this report but in brief we targeted seven changes, in (1) mothers' parenting techniques and disciplinary practices, (2) mothers' awareness of their children's developmental abilities, (3) beliefs that mothers held that led to dangerous parenting, (4) the anger mothers experienced in interaction with their children, (5) acceptance of the parent role (parent = the person responsible for the child's safety and welfare), (6) acceptance of the mother role (mother = the nurturing, affectionate figure for the child), and (7) the parents' own sense of efficacy.
2. To create an effective screening method for recruiting women who demonstrated all four of the risk factors identified, including low income, having a young (18 month to 59 months) child, having anger toward the child, and using physical discipline.
3. Intramural funding was attained to assess the extent to which self-monitoring in the form of a daily diary, in the absence of other treatment, might influence changes in each of the conceptual domains (a finding suggested by large changes experienced by the control group from pretreatment to posttreatment in the original study but not supported in a study measuring diary alone versus a true control with no-diary. This group received only pre-, posttreatment, and follow-up measures). The addition of this second control group showing no difference from the original diary only control allowed us to collapse the no-diary control group with the initial control group and increased our statistical power to detect preventive treatment effects at one-year follow-up as well as posttreatment.
4. To develop an affordable treatment that would influence each of the seven domains identified by our conceptual model as problematic in maltreating families. In addition, to create a fully manualized version of this treatment, including all handouts and note taking prompts to the mothers, scripts for a Group Facilitator, Home Visitor, and Phone Support person, all daily diaries used by the mother, and any other materials used in the program. These materials, enclosed as Appendix 1, will be available either on computer disk or hard copy to be purchased at the cost of copying and mailing only, to afford maximum access to our program.
5. To compare 90 minute home visiting with a 20 minute telephone contact as adjuncts to group treatment, to ascertain the extent to which the much more expensive home visiting was superior to empathetic telephone contact at home in each of the seven hypothesized domains.
6. To examine several "spin of P" projects, by looking at selected patterns of the data, such as sexually abused women in the sample (who appear to be more likely to be involved in mutual domestic violence) and women with a history of substance abuse (who, surprisingly are less likely to leave treatment than women without such a history). These projects will not be discussed in much detail in the Executive summary due to the complexity and length this would add, but it is important to acknowledge these products.

Study Design and Methods

There were two major studies, each of which involved women who acknowledged in a screening interview all four of the risk factors hypothesized. Because attrition from past intervention studies has been so high, each study overenrolled the number of women who actually completed the analysis. Only those women completing pretreatment, posttreatment, and follow-up were included in the final analyses for most variables. For each study, several of the domains were explored. For the single variable that has been the principle focus of past studies, parenting techniques and discipline, we utilized more than one measure in the first domain (parenting and discipline) in the current study. A clinical interview that identified three specific variables (harsh discipline, gentle discipline, and spanking) and a daily diary was used to evaluate daily discipline measures such as ignoring, spanking, and time-out. For the other domains, we utilized the one measure identified in Study One as the instrument most sensitive to change in a prevention study. Each study relied on three repeated measures (contrasting pretreatment versus posttreatment, and then pretreatment versus one-year follow-up). All seven domains were measured at pretreatment and posttreatment, and five of the measures were included at one-year follow-up. Because of the expense of the observational measures for Parent and Mother Role, and the necessity for another reliability observer, these were not repeated at one-year follow-up. Specifics of the design of each study included:

Preliminary Comparison of Control Groups. Due to improvements in the diary contrast in Study One across time, a study

was conducted with a single true control group receiving only the pretreatment, posttreatment, and one-year follow-up. This control group was contrasted with the original diary only group from Study One, and ultimately because of relatively no differences, the contrast and control groups were combined to increase the power for Study One.

Study One. A randomly assigned diary assessment only contrast group plus the no-diary control group was compared with a diary plus group and home visiting treatment group.

Study Two. The second study examined diary plus group treatment and home visiting (similar to Study One), in contrast to a second randomly assigned treatment group receiving diary plus group treatment and telephone contact. In other words, this study contrasted two treatment groups that differed only in terms of whether they received expensive home visiting versus the much more economical telephone contact treatment.

Findings

Preliminary Comparison of Control Groups. Because of increases seen in the initial control group that received a clinical interview and daily diary, a second, intramurally funded control group that did not receive the potentially clinically relevant interview questions or diary (nor did they receive the expensive Maternal Behaviors observation) was compared with the initial control group. Data indicated that the two groups were not different at pre- or posttreatment, except for changes in Parent Self-Efficacy. There was a decrease in Parent Self-efficacy in the no-diary and an increase in the diary group. As such a difference would favor the control group against the experimental group in subsequent analyses and as no other differences were found, the two groups were combined to increase power in Study One.

Study One. This study utilized group comparisons from pretreatment to posttreatment for the group plus home visitor treatment versus the two combined control groups just described. There were marginally significant to highly significant differences for the influence of treatment, with greater improvement in the treatment group ($p < .06 - .0001$) in five of the seven domains (with no time effects only for the anger measure). A similar comparison from pretreatment to one-year follow-up again showed similar significant effects, with all time measures reaching high levels of significance in the three measures used, except for anger, where $p < .07$. Parenting Strategies, Parent Affect, and Parent Self-efficacy continued to show superior findings for the treatment group over the control group. Interestingly, the more age dependent constructs of Developmental Awareness and Parenting Beliefs no longer showed treatment effects. As in suggestions for conduct disordered children, this may indicate the need for booster sessions to maintain gains as the children mature.

Study Two found that the treatment group receiving diary, group treatment and 90 minute weekly home visiting improved significantly over the group receiving diary, group treatment, and empathetic 20minute weekly telephone contact on only two of the five measured variables at posttreatment, that of Parent Self-efficacy; six of the findings showed no differences at follow-up. Only Parent Self-efficacy continued to show an improvement. Isolating the findings, at least in the context of supporting diary and group treatment, expensive and extensive home visiting does not appear to be superior to the less expensive and time consuming telephone contact in prevention of most abuse related variables.

Recommendations

The dissemination of our diary plus group treatment and weekly contact seems worthwhile, given the clear superiority at posttreatment over even the diary only group. Booster sessions, probably using telephone contact seems indicated. Another suggestion might be to delete the group treatment and disseminate the treatment materials directly to the women with one or two home visits to assess their home situation and to establish a personal relationship. Then, weekly treatment sessions could be mailed to the women with a follow-up home contact. The rationale for reducing the treatment to its lowest effective common denominator is that it is most likely to have widespread adoption if it is inexpensive. Prevention programs have an uphill battle in adoption, as the limited funds available are usually used to promote treatment rather than prevention. The old adage "an ounce of prevention. . ." seems applicable here, especially if it can be made affordable and easily disseminated.

Products To Date

Articles

DiLillo D, Tremblay GC, Peterson L. 2000. Linking childhood sexual abuse and abusive parenting: the mediating role of

maternal anger. *Child Abuse and Neglect* 24(6):767-779.

Peterson L. 1997. Behavior therapy's promise for child treatment: Where we've been, where we may be going. *Behavior Therapy* 28:531-541.

Peterson, L. 1995. Current directions in assessment of abused children: Introduction to the special series. *Behavior Therapy* 26:573-577.

Peterson L, Brown D. 1994. Integrating child injury and abuse/neglect research: Common histories, etiologies, and solutions. *Psychological Bulletin* 116(2):293-315.

Peterson L, Gable S, Doyle C, & Ewigman B. 1997. Beyond parenting skills: Battling barriers and building bonds to prevent child abuse and neglect. *Cognitive and Behavioral Practice* 4:53-74.

Peterson L, Gable, S, Saldana, L. 1996. Treatment of maternal addiction to prevent child abuse and neglect. *Addictive Behaviors* 22:1-13.

Peterson L, Tremblay G. 1999. Importance of developmental theory and investigation to research in clinical child psychology. *Journal of Clinical Child Psychology* 28:448-456.

Peterson L, Tremblay G.. 1999. Self-monitoring in behavioral medicine: Children. *Psychological Assessment* 11:458-465.

Chapters

Brown D, & Peterson, L. 1997. Unintentional injury and child abuse/neglect. In R Ammerman, M Hersen, eds., *Handbook of prevention and treatment with children and adolescents: Intervention in the Real World Context* (pp. 332-356). New York: John Wiley & Sons.

Peterson, L. 1997. Child physical abuse. In S Gall, ed., *Encyclopedia of the Child and Child Development*. Pike, OH: Eastwood Publications.

Peterson L, & Gable S. 1998. Holistic injury prevention. In J Lutzker, ed., *Child Abuse: A Handbook of Theory, Research, and Treatment* (pp. 291-318). New York: Plenum.

Presentations

DiLillo D, Damashek A, Peterson L. 1998. *Development of a scale to assess parental supervision of children's injury-relevant behaviors*. Presented at the Annual Conference of the Association for the Advancement of Behavior Therapy, Washington, DC.

DiLillo D, Giuffre D, Tremblay GC, Peterson L, Steinley D. 1999. *Physical conflict in the romantic relationships of women with a history of childhood sexual abuse*. Presented at the Meeting of the Association for Advancement of Behavior Therapy, Toronto, Canada.

Gable S. 1996. *An affective, interpersonal approach to enhancing mother-child relationships: Application and efficacy*. Presented at the Head Start's Second National Research Conference: Translating Research into Practice, Washington, DC.

Gable S, Jacobi K. 1995. *Mom-kid trial: A path to rewarding parenting*. Presented at the Strengthening Families Across the Spectrum Prevention Conference, Jefferson City, MO.

Gable S, Llorens MB, Peterson L. 1994. *Effecting child compliance: Validation of a short, structured measure of parenting strategies*. Presented at the Kansas Conference in Clinical Child Psychology, Lawrence, KS.

- Gable S, Peterson L. 1997. *Estimating increases in the positives: An essential component in evaluating child abuse prevention programs*. Presented at the Annual Conference of the Society for Research in Child Development, Washington, DC.
- Gable S, Peterson L. 1995. *The theoretical and practical significance of studying parents' efforts at socializing safe behavior in toddlers*. Presented at the Biennial Meeting of the Society for Research in Child Development, Indianapolis, IN.
- Lutzker J, Peterson L, Donahue B, Sanders M, Hansen D, Azar S, Ammerman R. 1996. *Child abuse and neglect: The cutting edge*. Presented at the Annual Conference of the Association for Advancement of Behavior Therapy, New York NY.
- Newman E, Holtzworth-Munroe A, Keane T, Lisman S, Brandon T, Peterson L. 1996. *Research ethics: Ethical dilemmas encountered when conducting research with "at-risk" samples*. Presented at the Annual Conference of the Association for Advancement of Behavior Therapy, New York NY.
- Peterson L. 1997. *Cognitive and affective interventions with mothers for abuse and neglect*. Presented at the Annual Conference of the American Psychological Association, Chicago, IL.
- Peterson L. 1997. *Drawing a line between injury vs. abuse*. Presented at the University of Missouri-St. Louis, St. Louis, MO.
- Peterson L. 1996. *Prevention and treatment of child abuse and neglect: In-depth intervention for parental vulnerability*. Presented at the Annual Conference of the Association for Advancement of Behavior Therapy, New York, NY.
- Peterson L. 1996. *Treatment of maternal addiction to prevent child abuse and neglect*. Presented at the Addictions '96, Hilton Head, SC.
- Peterson L. 1995. *Prevention and treatment of child abuse*. Presented at the Annual Conference of the Association for Advancement of Behavior Therapy, Washington, DC.
- Peterson L. 1995. *Prevention of childhood disorders: An overview and a lethal example*. Presented at the Annual Conference of the American Psychological Association, New York, NY.
- Peterson L. 1995. *Out of harms way: Preventing abuse and neglect through bonding, networking, self-contracting, skill building and reinterpreting the child*. Presented at the World Congress of Behavioural and Cognitive Therapies, Copenhagen, Denmark.
- Peterson L. 1995. *Crossroads of child abuse, neglect, and injury: Parental, community, and societal contributions to child deaths*. Presented at the World Congress of Behavioural and Cognitive Therapies, Copenhagen, Denmark.
- Peterson L. 1995. *Dimensions underlying a skill-based child abuse/neglect model*. Presented at the University of Oklahoma's Departmental Teaching Conference, Oklahoma City, OK.
- Peterson L. 1995. *Child injury: Developmental application of the stress-diathesis disease model to psychosocial prevention*. Presented at the Society of Behavioral Medicine's 16th Annual Scientific Sessions, San Diego, CA.
- Peterson L. 1994. *Child abuse intervention: Can we collect good data and provide real treatment?*. Presented at the Annual Meeting of the Association for Advancement of Behavior Therapy, San Diego, CA.
- Peterson L. 1994. *Preventing parenting failures in high risk parents: A multigoal multicomponent approach*. Presented at the Annual Meeting of the American Psychological Association, Los Angeles, CA.
- Peterson L. 1993. *Child maltreatment: Reporting, understanding child risk intervention and deciding to terminate parental rights*. Presented at the 27th Annual Association for Advancement of Behavior Therapy Convention, Atlanta, GA.
- Peterson L. 1993. *Childhood injury and child abuse/neglect: The need for integration*. Presented at the Florida Conference

on Child Health Psychology, Gainesville, FL.

Peterson L. 1993. *Child abuse/neglect is injury and much injury is child abuse/neglect*. Presented at the University of Oklahoma, Oklahoma City, OK.

Peterson L, Gable S. 1996. *A mother's diary: Treatment effects on daily discipline in mothers at risk for abuse*. Presented at the Sixth Annual Convention of the American Association of Applied and Preventive Psychology, San Francisco, CA.

Peterson L, Lutzker J. 1997. *Prevention and treatment of child abuse and neglect: Indepth interventions*. Presented at the Annual Conference of the Association for the Advancement of Behavior Therapy, Miami, FL.

Peterson L, Tremblay G, Saldana L. 1998. *Successful child abuse prevention in women with substance problems*. Presented at the Annual Scientific Meeting of the Research Society on Alcoholism, Hilton Head, SC.

Peterson L, Tremblay G, Saldana L. 1997. *Child abuse and substance abuse*. Presented at the Florida Conference on Child Health Psychology, Gainesville, FL.

Saldana L, Gable S, Peterson L Clinical Child Psychology, Lawrence, KS.. 1996. *Alcohol disorders in low-income. at risk mothers: Another target topic for child abuse prevention*. Presented at the Kansas Conference in Clinical Child Psychology, Lawrence, KS.

Tremblay G, Jacobi K, Peterson L. 1997. *Recruitment and retention of at-risk samples in clinical research: Observations from a child abuse prevention program*. Presented at the Annual Conference of the Association for Advancement of Behavior Therapy, Miami, FL.

Tremblay G, Nainys M, Peterson L. 1997. *Assessing instructional style among mothers at risk for child maltreatment*. Presented at the Florida Conference on Child Health Psychology, Gainesville, FL.

Tremblay GC, DiLillo D, Peterson L. 1999. *Disentangling the effects of childhood sexual and physical abuse on parenting*. Presented at the Meeting of the Association for Advancement of Behavior Therapy, Toronto, Canada.

Tremblay GC, Lopez C, Gable S, Peterson L. 1996. *Problem solving for problem solving assessment: Moving toward validation of a measure for high risk parents*. Presented at the Kansas Conference in Clinical Child Psychology, Lawrence, KS.

on the socioeconomic differences in child-rearing and parenting behavior and the effects of these differences on child development is often interpreted as being descriptive of normative patterns of parenting and child development in African-American populations. Research in which the child-rearing and child development of African-American groups are compared with that of the white middle class has been criticized as an inadequate means of elucidating the developmental processes of Black children. Criticisms have included (1) that race-comparative research hinders "the development of a rich and meaningful knowledge base about Afro-American children qua Afro-American children"; (2) that race-comparative studies foster the perception that African-American children are "abnormal, incompetent, and changeworthy" ; (3) that race-comparative research fosters "victim blaming" by focusing on characteristics of the individual rather than considering situational determinants of those characteristics; and (4) that race-comparative studies conducted to date have not effectively disentangled the effects of race from the effects of socioeconomic status. A valid approach to the development of a meaningful knowledge base of African-American child development must incorporate four characteristics. First, it must be culturally relevant to the lives of African-American children and their families. Second, it must incorporate a study of the contextual effects, both proximal and distal, which affect African-American families and the development of African-American children. Thirdly, the development of a knowledge base of African-American child development must include an attempt to disentangle the effects of economic hardship from cultural differences in the processes which influence developmental outcome. Finally, a valid approach to the study of the development of African-American children must address issues of racial identity as well as racial discrimination and how they affect African-American families and children. Our research addressed all these issues as well as examined the issue of residential context on parenting and child outcomes.

Research Questions or Hypotheses

The goal of the project is to study the ecological correlates of development in African-American infants and toddlers by examining how differences in the social and physical characteristics of neighborhoods affect the families and children who live there. The purpose of this project was to answer the following research questions:

Research Question 1: To use systematic ethnographic methods to develop and validate measures of parenting goals and attitudes for use with African-American populations across the spectrum of socioeconomic status.

Research Question 2: To examine how differences in the physical and social characteristics of neighborhoods are related to differences in parenting among African-American parents across the spectrum of socioeconomic status.

Research Question 3: To examine how differences in the physical and social characteristics of neighborhoods directly and indirectly (via effects on parenting) affect the developmental outcomes of African-American children across the spectrum of socioeconomic status.

Research Question 4: To identify characteristics of neighborhoods and families that are related to increased resilience of African-American children living in poverty.

Research Question 5: To explore how factors racial socialization, racial identity, and experiences of racial discrimination are associated with parenting and child development outcomes among African-Americans across the spectrum of socioeconomic status.

Study Design and Methods

We selected thirty-nine neighborhoods in Baltimore City that varied by socioeconomic status (i.e., average household wealth of the neighborhood) and racial composition. We created indicators of residential environment using secondary data sources and by collecting primary data using an observational protocol. We then sampled families within the thirty-nine study neighborhoods who had resided in the neighborhoods for at least 1 year and had children between the ages of 3 to 41/2. to measure parenting practices and beliefs and child cognitive outcomes.

We employed qualitative and quantitative methods to answer our research questions. We employed methods of multi-level modeling to examine associations between neighborhood characteristics and parenting and child outcomes.

Findings

The primary data collection effort for the characterization of neighborhoods yielded important information about residential contexts. The brief data collection protocol that we adapted and developed is easily implemented and yields reliable indicators of neighborhood territoriality, physical incivilities and available play resources for young children. Given that most primary data collection efforts are time and resource intensive, our protocol is an attractive alternative to existing neighborhood observational tools.

Our findings also yielded important information on parenting tasks and priorities among African American families and their racial socialization practices. African Americans must simultaneously negotiate three realms of experience: the mainstream, the minority, and the Black cultural experience. Therefore, it is assumed that the parenting priorities and socialization practices of African American parents might incorporate unique strategies designed to teach their children to be effective in these three different spheres. We developed an Africentric Home Inventory, a brief assessment of the music, toys, books and other items to communicate African American heritage. We also utilized the systematic qualitative methods of pile sorting and ranking to identify how African-American parents of preschool children conceptualize their role as parents and which parenting tasks they consider to be their highest priorities. Overall, African-American parents in this sample organized parenting tasks around five themes: Providing a Responsible Example, Values, Provide, Protect, and Teach. Furthermore, tasks associated with Providing a Responsible Example and teaching Values were identified as the most important tasks of parenting. Although there were some minor differences in this conceptualization by socioeconomic status of the primary caregiver, there were more similarities than differences.

In our sample, we found that the majority of our families incorporated racial socialization messages as a routine component of their parenting as evidenced by the scores on the Parent's Experience of Racial Socialization (PERS). Parents in our sample seemed to emphasize messages of cultural pride over messages of mistrust, and there was very little variation in the extent of messages conveyed by family income or education of the parent. We also examined the context of the home environment as part of the racial socialization process and found that the majority of families had Africentric items in the home. We found, as might be expected, that the Africentric home environment varied significantly by family income. Families with higher incomes had more Africentric items such as toys, books, magazines and music. The association between the Africentric home environment and family income may partially reflect differences in resource availability. The racial socialization practices and home environment were associated with child cognitive and behavioral competence even after accounting for level of parental involvement and socioeconomic status.

In a set of preliminary findings concerning research question 2-4, we found that there are neighborhood influences on parenting behaviors and child development outcomes. However, the neighborhood influences are, in our sample, selective in their effects. Although our findings are preliminary, this suggests that for some parenting practices and child development, the neighborhood environment plays a role in shaping those outcomes. These findings are very preliminary and the next few months will yield more solid findings with regard to the extent to which neighborhoods affect parenting behaviors and child development.

consume a disproportionate share of child health resources. Chronic and disabling conditions can have a profound effect on children's quality of life.

Research Questions or Hypotheses

This project aimed to implement and evaluate a 15-month, parent-professional intervention designed to decrease risk for psychological symptoms in children with four chronic illnesses (cystic fibrosis, sickle cell anemia, diabetes, and moderate-severe asthma) aged 7 to 10 and their parents. The program was evaluated using a randomized controlled clinical trial design, with a two-stage recruitment process that served to identify and follow families who did not wish to join an intervention program but were willing to participate in a research effort. The specific aims of the study were to: 1) assess the intervention's success in reaching specific objectives; 2) assess the intervention's impact on participants' mental health; and 3) document which children and parents benefited the most.

In addition to its primary goal of program evaluation, the project offered opportunities for developing and assessing measurement strategies for critical concepts pertaining to this field. In addition to reporting the primary outcomes of the program evaluation, the comprehensive final report also describes the results of our measurement studies.

Study Design and Methods

We implemented and evaluated a theory-driven, community-based, parent-professional intervention to decrease risk for psychological symptoms in children with chronic illnesses aged 7 to 10 and their parents. The intervention was delivered through a structured protocol by a team consisting of a child life professional and a "veteran parent" (a parent who has raised a child with a chronic illness). The specific objectives of the intervention were 1) to strengthen two important sources of self-esteem (body-esteem and perceived social acceptance) in children and 2) to enhance specific types of support (informational, affirmational, and emotional) and a sense of parenting efficacy in mothers. The child life professional worked with enrolled children; the veteran parent worked with their mothers. The intervention focused on children with one of four chronic conditions (diabetes, sickle cell anemia, cystic fibrosis, and moderate to severe asthma) and their parents, but was designed for replication in clinics serving children with any ongoing serious physical health condition.

The intervention was evaluated using a longitudinal, repeated measures, randomized controlled clinical trial design. Letters were sent to 565 patients, inviting them to participate in the study. One-hundred-seventy-four (31 %) were unable to be contacted and 115 (20%) were ineligible (outside geographic area, mental retardation, language difficulties, asthma severity criteria). Fifty-seven (20%) refused to participate and 26 were unable to be scheduled for an interview within the interview period. Onehundred-ninety-three interviews were completed. Of these families, 32 (17%) refused to be randomized.

Differences between the refused randomization group and both the experimental and the control groups were described.

We conducted two, parallel sets of analyses: one focused on maternal outcomes; the other on child outcomes. We approached each set in essentially the same manner, but used different variables as appropriate. First, using t-tests, we examined whether the experimental and control groups were comparable at baseline in order to check the results of randomization. We also performed a logistic regression to determine if there were significant differences between the refused randomization (RR) and the program participation (PP) groups. To answer the question of whether the RR group changed in respect to the mental health and social support variables, paired t-tests were completed using data from the baseline and the follow-up interview. T-tests were conducted to identify differences among the Refused Randomization, Low Participation and High Participation groups on key demographic, condition-related, resource, and adjustment variables. ANOVAs were not conducted because of the differences in sample sizes among the groups. Second, using analyses of variance, we examined whether mental health outcomes varied by intervention group and baseline characteristics. Third, we assessed the effect of the intervention on selected mental health variables using multiple regression models. We used stepwise multivariate analyses, first with selected covariates measured at baseline and then with selected interactions. Examination of interaction terms allowed us to determine whether the intervention had differential effects for subgroups of mothers or children.

Findings

Maternal anxiety scores for participants in the experimental group decreased during the intervention period for all diagnostic groups and for the total group; scores for the control group increased ($F=5.07$, $p = .03$). In multiple regression analyses, intervention group was a significant predictor of post-test anxiety scores ($p < .05$). Effects were greater for mothers with high

baseline anxiety ($p < .001$) or who were themselves in poor health ($p < .01$).

Overall, these results demonstrate the effectiveness of our intervention in reducing symptoms of anxiety in mothers of children with selected chronic illnesses; the effect was especially pronounced for mothers who were highly anxious at baseline or who were in poor health themselves. The intervention had a similar effect for all of the four selected conditions, suggesting that it could be effective for mothers of children with other chronic illnesses. The intervention did not have an effect on depression, in part because this group of mothers reported low levels of depression at baseline. The intervention appeared to have direct effects on maternal mental health status; no evidence of indirect effects (i.e., by enhancing social support) was found.

Our results also show that mothers who elect not to participate in a prevention program report better functioning and mental health for both themselves and their child compared to mothers who elect to participate. Many program refusers are functioning quite well and continue to do so over time. These mothers may believe that the kind of support programs that we offered them were not particularly needed.

The intervention also had a significant main effect ($F=9.79$, $p<.01$) for children. Children in the experimental group showed better adjustment post-intervention than children in the control group. The effect of the intervention was especially striking for children who had low physical self-esteem at baseline. Children in both the experimental and control groups were assigned to be in a low self-esteem group or a high self-esteem group, based on baseline physical self-esteem scores. We examined the change in adjustment scores for each of the four groups (experimental/control by high/low self esteem). Mean adjustment scores for the low physical self-esteem, experimental group children increased from 66.69 at baseline to 68.52 at post-test (T2); however, mean scores for the low physical self-esteem, control group children decreased from 67.24 at baseline to 63.14 at T2. Mean adjustment scores for the high physical self-esteem experimental group children increased from 69.77 at baseline to 71.35 at T2; high physical self-esteem, control group children's mean adjustment scores remained essentially the same (69.88 vs. 69.73).

Recommendations

This study suggests that enhanced access to well-designed family-to-family interventions that incorporate both child and parent components will contribute to quality of life for the family. State Title V CSHCN programs and clinical subspecialty centers should consider developing and implementing these kinds of programs.

Products To Date

Articles

DeVet KA, Ireys HT. 1998. Psychometric properties of the maternal worry scale for children with chronic illness. *Journal of Pediatric Psychology* 23(4):257-266.

Ireys HT, Perry JJ. 1999. Development and evaluation of a satisfaction scale for parents of children with special health care needs. *Pediatric* 104(5):1182-1191.

Dissertations and Theses

Immelt S. 1999. Perceived self-competence of school-aged children with chronic medical conditions. Doctoral dissertation. School of Nursing, Johns Hopkins University..

Kissel A. 1999. Evaluation of a social support program for children with chronic medical conditions and their mothers: A cost-effectiveness and cost-benefit analysis. Doctoral dissertation. Department of Psychology, American University..

Perry D. 2000. Depression in mothers and children exposed to chronic stress. Doctoral dissertation. Department of Population and Family Health Sciences, School of Hygiene and Public Health, Johns Hopkins University.

Presentations

Chernoff R, Ireys H, DeVet K. 1997. *Caring for children with a chronic condition: Accentuate the positive!*. Presented at the Ambulatory Pediatric Association, Washington, DC.

DeVet KA, Ireys HT. 1998. *Building community resources: The craft of training lay intervenors*. Presented at the Society for Prevention Research, Park City, UT.

Munn EK, Widener MA. 1998. *The K.I.D.S. program: Child life working in the community*. Presented at the Child Life Council, Kansas City, MO.

Munn EK, Widener MA. 1998. *Network mother/child life specialist team collaboration in the community*. Presented at the Association for the Care of Children's Health, Kansas City, MO.

Research Questions or Hypotheses

This study tested the following hypotheses related to maternal nutritional exposures and the outcome of twin gestation: Newborn size of twins increases as maternal caloric balance and nutrient density of diet increase, mean gestational age of twins increases as estimated caloric balance and nutrient density of maternal dietary intakes increase, and twin newborn size increases as the rate of pregnancy weight gain and total weight gain increase.

Study Design and Methods

Women were recruited into the Prospective Investigation of Twin Gestation (called the "Diana 11 Project") through collaboration with Twins Magazine. Between 1996 and 1998, all new subscribers stating on subscription inquiry cards that they were pregnant with twins were sent a recruitment letter. In order to be eligible for enrollment, women had to return an interest survey and be pregnant with twins for less than 24 weeks. Of 4,500 recruitment letters sent, 2,155 women (49.7%) returned the eligibility and interest survey, 1,716 women were eligible and interested in participating, and 66,000 (1,127) returned signed consent forms. Ultimately, 988 women (88%) completed the study. Women completing and not completing the study did not differ in age or parity, but women who did not complete the study were more likely to be other than white and to have lower educational levels. The sample was comprised primarily of white (93%), educated (63%, college educated), married (97%), and nonsmoking (94%) women. Approximately 60% were nulliparous, and 48% reported use of assisted reproductive therapy.

Study participants were asked to complete questionnaires regarding dietary and supplement intake, energy expenditure, pregnancy symptoms, body weight, height, and exposures to alcohol and tobacco following their 2nd, 4th, 6th, and 8th months of pregnancy. Information was requested for each month that had passed since the last form was returned, and for the month before conception. Information on gestational age at delivery was obtained from health care providers and from mothers. Other variables ascertained included the mother's race, education, smoking status, parity, marital status, annual household income, age, and assisted reproductive treatment.

Findings

Investigations related to the first hypothesis on effects of maternal dietary intake on newborn size began with a description of diets of women pregnant with twins (Diana 11) and proceeded with comparison of intakes with women delivering 660 S1116letolis from a similar study (Diana P) that used the same dietary assessment tool. Prior to pregnancy, women expecting twins had significantly higher ($p < 0.05$) mean intakes of calories, protein, carbohydrate, fat, cholesterol, omega-3-fatty acids, 6 of 8 vitamins, and 2 of 4 minerals than women with singleton pregnancies. These results were not explained by differences in maternal weight status or physical activity level. By the 8th month of pregnancy, intakes of women with twins were significantly higher than singleton pregnancies for kcal (by 6%), the energy nutrients (by 5 to 15%), cholesterol, omega-3-fatty acids, 2 of 8 vitamins, and 2 of 4 minerals. Results indicate that caloric and nutrient intakes tend to be higher in twin than singleton pregnancies before and throughout pregnancy. The effect of dietary intake on newborn size outcomes was evaluated by comparing dietary intake of women delivering "optimal" (both twins with weights between 2500-3000 g, $n = 183$) and non-optimal" outcomes (one or both twins were not in this birthweight range, $n = 662$). "Optimal" outcomes were further characterized by the absence of hypoglycemia at birth (to control in part for newborn thinness), infection, and livebirth status. Average caloric intake and intake of foods within 22 food groups across pregnancy were evaluated. Differences in caloric intake by newborn outcome was not apparent in these analyses, however, intake of several food groups differed by newborn outcome. Specifically, women who delivered two infants within the "optimal" range of birthweight consumed on average significantly more ($p < 0.05$) servings of water each day (4.7 vs. 4.2 servings), dairy products (2.3 vs. 1.7 servings/day), fruits (2.6 vs. 2.2 servings/day), fish (0.27 vs. 0.21 servings/day), and fewer processed meats (0.43 vs. 0.33 servings/day). These results suggest quality of maternal diet may influence twin outcomes in ways that appear to be unrelated to caloric intake but related to nutrient density.

Results related to the second hypothesis indicate that rate of weight gain, a proxy measure of caloric balance, is related to gestational age. Gestational age was 1.0 to 3.7 days shorter for women gaining at the lowest quartile of rate (0.9 lbs./week) versus higher rates of gain. This effect is strongest before 241 days gestation. Newborns of women with the lowest rates of gain

between conception and 241 days have gestational ages that averaged 5.1 days less than newborns of women who gained at higher rates.

Results related to the third hypothesis indicate that mean birthweight of twins increases significantly as rate of gain and total weight gain in pregnancy increase. In multiple regression analyses controlling for effects of maternal age, parity, body mass index, height, fertility treatment; and infant sex and zygosity, a one pound increase in average rate of weight gain in pregnancy predicted a 146 g increase in the mean weight of newborn twin pairs. While controlling for effects of gestational age, each pound increase in total weight gain in twin pregnancy predicted a 4.3 g increase in mean birthweight. Timing of pregnancy weight gain was important. Each pound/week of weight gain in the first half of pregnancy predicted a 48 g increase, whereas it predicted an 80 g increase in mean birthweight in the second half of pregnancy.

Other Results

In other studies, analyses have shown that:

- a) Only 60% of women received advice on total weight gain in twin pregnancy from a health care provider, and 64% of the time the advice corresponded to the Institute of Medicine's (IOM) 1990 recommendation. The percentages of women gaining within the IOM range of 35 to 45 pounds did not vary by whether or not they received weight gain advice. Amount of weight gain was, however, associated with weight gain advice.
- b) Using standardized instructions developed as part of the Diana 11 Project, parents can measure infant head, midarm, and abdominal circumference with acceptable precision. These validated techniques were used for assessment of the growth of twins at approximately 6 months of age.
- c) A number of clinical complications and common symptoms of pregnancy occur more often among twin than singleton gestations. These conditions and symptoms include pregnancy-induced hypertension, gestational diabetes, preterm labor, iron deficiency anemia, heartburn, constipation, fever, headache, nausea, and vomiting
- d) Twins conceived through assisted fertility measures weigh less at birth than twins conceived naturally
- e) Preliminary results indicated the women who developed gestational diabetes during their twin (gestation weighed significantly less at birth than women who did not develop gestational diabetes.

Results of studies given in this summary should be considered preliminary until papers reporting the results are accepted for publication.

Recommendations

It is possible that outcomes of twin gestation could be improved given increased attention to maternal dietary quality and health professional advice to gain weight at rates above 0.7 lbs per week in the first half of pregnancy. Such advice may be particularly important for women receiving fertility assistance measures because of lower birth weights of these infants. Women bearing twins may benefit from increased anticipatory guidance on prevention and management of gestational diabetes, nausea, vomiting, heartburn, constipation, and other disorders occurring more often in them than in singleton pregnancies.

Products To Date

Abstracts

Brown JE, Murtaugh MA, Margellos HC, Olson CK. 2000. Dietary intake differences between women expecting twins and singletons. *Abstracts of the Federation of American Societies for Experimental Biology (FASEB)*.

Margellos HC, Brown JE, Murtaugh MA, Olson CK. 2000. Weight gain advice received by women pregnant with twins. *Abstracts of the Federation of American Societies for Experimental Biology (FASEB)*.

Murtaugh MA, Brown JE, Margellos FIC, Olson CK. 2000. Growth of infants conceived with assisted fertility. *Abstracts of the Federation of American Societies for Experimental Biology (FASEB)*.

Olson CK, Brown JE, Murtaugh MA, Margellos HC. 2000. Symptom comparison of singleton and twin pregnancies. *Abstracts of the Federation of American Societies for Experimental Biology (FASEB)*.

Articles

Bradley JL, Brown JE, Himes JH. 2001. Reliability and validity of parental measurements of infant size. *American Journal of Human Biology* 13:275-279.

Brown JE, Carlson M. 2000. Nutrition and multifetal pregnancy. *Journal of the American Dietetic Association* 100(3):343-348.

Dissertations and Theses

Bradley J. 2000. Reliability and validity of prenatal measurements of infant size. Master's thesis, Public Health and Nutrition, University of Minnesota, Minneapolis, MN.

Margellos, H. 2000. Weight gain advice and actual weight gain among women expecting twins. Master's thesis, Epidemiology, University of Minnesota, Minneapolis, MN.

Olson C. 2000. Symptom comparison of singleton and twin pregnancies. Master's thesis, Maternal and Child Health, University of Minnesota, Minneapolis, MN.

Quale M, Kiel S. 2000. Birthweight of women who develop gestational diabetes in twin pregnancy. Master's thesis, Certified Nurse Midwife Program, School of Nursing, University of Minnesota, Minneapolis, MN.

Presentations

Brown J. 1999. *Nutrition and multifetal pregnancy*. Presented at the Arkansas MCH and WIC Conference, .

Brown J. 1999. *Nutrition and multifetal pregnancy*. Presented at the Virginia WIC Conference, .

Brown J. 2000. *Nutrition and multifetal pregnancy*. Presented at the National Maternal Nutrition Intensive Course, .

Brown J. 2000. *Nutrition and multifetal pregnancy*. Presented at the National Association of WIC Directors, Salt Lake City, UT.

Brown J. 2001. *Nutrition and multifetal pregnancy*. Presented at the Stanford University's Neonatal and Pediatric Nutrition Update Conference

levels in AA children than in MA children and others showed no difference in BP levels between these two ethnic groups. One study showed BP levels to be higher in MA than in AA children. Diverse methodology used in different studies, including limited age groups studied, may be the major cause of the differences among the reports. A recent report of meta-analysis of previously published data suggests that BP levels of black children and adolescents, especially females, are higher than in other racial groups, but this analysis does not show whether a significant part of the difference is related to the differences in body weight or other measures of body size.

Research Questions or Hypotheses

1. To establish normative auscultatory BP levels using the width of the BP cuff 40% to 50% of the circumference of the arm.
2. To examine for possible ethnicity- and/or gender-related difference among African American (AA), Mexican American (MA) and non-Hispanic white (NHW) females and males in kindergarten through 12th grade.
3. To obtain normative oscillometric BP values and to examine differences in BP levels obtained by the auscultatory and the oscillometric methods.
4. To obtain anthropometric measurements that are known to influence BP levels.
5. To assess dietary history and physical activities in children and adolescents, which affect BP levels through overweight.

Study Design and Methods

This study was a descriptive correlational study. A field study approach was used to obtain normative BP levels by the auscultatory and the oscillometric methods in a wide age ranges of children and adolescents of the three major ethnic groups. The data was analyzed to examine the correlation of BP levels with various variables including ethnicity, gender, anthropometric measurements, (weight, height, body mass index, and triceps and subscapular skinfold thicknesses), and diet history and physical activities which may affect BP levels through overweight. BP levels obtained in three School Districts were pooled with previously obtained BP data (from the San Antonio Biethnic Children's Blood Pressure Study) for the final analysis of BP levels for the triethnic population. Children were assigned randomly to one of two methods for blood pressure measurement. Three auscultatory and three oscillometric readings were done using the appropriately sized cuff. Other measurements (height, weight, triceps and subscapular skinfold measurements, and pulse) were taken. The health behavior and history questionnaires were completed and diet history was done. Data was recorded on paper for later coding and computer entry.

Population Description and Sampling Plan

This study was carried out in school children who are enrolled in kindergarten through 12th grade, in the South San Antonio Independent School District (ISD), the Schertz-Cibolo-Universal City ISD, and in six selected schools in the San Antonio ISD. Data from a total of 7269 children ranging in age from 5 through 17 years are included in the statistical analysis. Overall, the number of MA children was much greater (58.9%) than that of NHW (28.0%) and AA (13.1%) children. All children who assented and whose parents consented were included in the project, although not all were included in the data analysis. Children who were not in one of the three ethnic groups being studied were not included in data analysis nor were those with certain health problems or medications known to affect blood pressure. In some age groups studied, there were insufficient numbers of African American children. This was due mostly to smaller numbers of these students available in the San Antonio school districts.

Findings

1. Auscultatory (AUS) findings: The sequence of AUS BP readings showed no systematic differences. AUS systolic pressure (SP) correlated best with weight ($r = 0.705$ for boys and $r = 0.583$ for girls), followed by height ($r = 0.660$ for boys and $r = 0.583$ for girls) and age ($r = 0.615$ for boys and $r = 0.539$ for girls). For SP, AA girls showed almost always significantly ($P < 0.05$) higher SP levels than those of MA and NHW girls for ages 5 through 11 years. MA girls showed only a tendency for higher SP levels than NHW girls ($P > 0.05$). No consistent or significant ethnic difference was found for boys. When the SP data were adjusted for weight, the majority of ethnic differences disappeared, suggesting that the ethnic difference in SP

was mostly due to the difference in weight. In subjects 13 years and older, SPs in boys were commonly and significantly ($P < 0.05$) higher (3 to 9 mm Hg) than those of girls for the three ethnic groups. K4 diastolic pressure (DP) was inconsistently higher in MA and NHW preadolescent boys and girls than AA counterparts, with the lowest K4 DPs in AA children. Unlike with SP, gender difference K4 DP was biphasic with higher levels in girls initially (13 and 14 years) followed by higher levels in boys later (16 and 17 years). Findings similar to those for K4 DPs were present for K5 DP levels. Since the ethnicity-related differences in SP and DP were clinically unimportant, BP data for three ethnic groups were combined and presented as normative BP data separately for boys and girls.

2. Oscillometric (OSC) findings: No important differences in OSC BP levels were found with the order of the BP method used. Systolic pressure (SP) levels were most closely correlated with weight ($r = 0.639$ for boys and $r = 0.500$ for girls) followed by height ($r = 0.594$ for boys and $r = 0.477$ for girls) and age ($r = 0.559$ for boys and $r = 0.418$ for girls). No consistent ethnic differences in SP were found in subjects 5 through 13 years of age. At ages 14 to 15, AA and NHW girls' SPs became significantly ($P < 0.05$) higher (3-4 mm Hg) than those from MA girls. No ethnic difference was found for boys. Significant ($P < 0.05$) gender difference in SP was present in subjects between 13 and 17 years, with higher SP in boys than in girls (up to 11 mm Hg). Since the differences in SP levels were not consistently different or clinically important among the ethnic groups, BP data were pooled together and normative percentile values developed for boys and girls. OSC SP was 9 to 11 mm Hg higher than AUS SP throughout the age groups studied. OSC DP was 1-4 mm Hg lower than K4 DP and about 4-5 mm Hg higher than K5 DP.

3. Anthropometric findings: No consistent ethnic differences were found in weight, although AA preadolescent boys and girls showed a tendency to be heavier than MA and NHW children did. AA and NHW boys and girls showed a tendency to be taller than MA counterparts, frequently reaching statistical significance ($P < 0.05$) throughout the ages studied. Between ages of 13 and 17 years, AA and NHW boys and girls were often significantly ($P < 0.05$) taller than their MA counterpart ($P < 0.05$). The BMI values of MA boys were almost consistently, significantly ($P < 0.05$) larger than NHW boys and showed a tendency to be larger than AA boys, beginning as early as age 6 and continuing through age 17. For girls, a similar ethnic difference was noted as in boys, although rarely significant, throughout the ages studied, with the smallest BMI seen in NHW girls. No consistent significant ethnic differences were present in the triceps skinfold thickness for both boys and girls. Unlike the triceps skinfold, the subscapular skinfold remained more or less stable for boys whereas it showed a small increase in girls between ages of 10 and 17. The subscapular skinfold thickness for MA boys were significantly ($P < 0.05$) larger than that for NHW boys starting as early as 8 years of age and continuing till late adolescence. MA girls showed the largest subscapular skinfold thickness.

4. Nutritional and activity findings: NHW boys and girls reported a tendency for a larger caloric intake (kcal/kg) than MA and AA counterparts, occasionally becoming significant ($P < 0.05$), but caloric values were the lowest in 15-17 year old NHW girls. Preadolescent AA boys and girls had higher %CHO than other ethnic groups. Percent fat intake was lowest in AA girls. No gender difference was found for %CHO and fat intake. Cholesterol intake was larger in MA and AA children than in NHW children. Boys' cholesterol intake was larger than girls' were, especially in MA and NHW subjects. AA and MA boys and girls reported significantly longer hours of television (TV) viewing than NHW counterparts. 15% to 25% of AA and MA boys and girls 11 to 17 years old reported spending 4 hours watching TV, while only 5-6% of NHW counterparts reporting the same. AA boys and girls reported more organized sports hours (active hours) than other ethnic groups, with MA subjects reporting the shortest active hours.

Recommendations

This study provides normative auscultatory blood pressures using a blood pressure cuff 45-50% of the circumference of the arm for children ages 5-17 years in three ethnic groups. Additional testing of oscillometric devices must be completed before normative data obtained can be published. This study also shows those blood pressures obtained by auscultatory and oscillometric devices cannot be interchanged. Additional research should be done among African-American children, as the numbers from this study were not as large as needed to generalize.

The most important findings from this study show that children are becoming heavier and less active (as other studies have also shown). It is important that there be additional research in the behavioral and physiological arenas to determine how children become obese and remain obese. Interventions have been for the most part ineffective because the causes of childhood obesity are not fully understood. The problems resulting from obesity and inactivity contribute to most of the high cost chronic health problems in children and adults.

Products To Date

Articles

Menard S, Park M. 1995. Blood pressure measurement in children. *Seminars in Perioperative Nursing* 4(2):92-95.

Menard S, Park M, Schoolfield J. 1999. The San Antonio biethnic children's blood pressure study: Anthropometric findings. *Clinical Excellence for Nurse Practitioners* 3(1):19-27.

Dissertations and Theses

Park M. 1989. Stress, social support and abuse and neglect in high risk infants. Unpublished Master's thesis, University of North Carolina at Chapel Hill, Chapel Hill, NC.

Presentations

Menard S, Park M. 1997. *The San Antonio biethnic children's blood pressure study research based nursing practice*. Presented at the , Jyvaskyla, Finland.

Menard S, Park M. 1996. *The San Antonio biethnic children's blood pressure study: Findings and implications for nursing*. Presented at the Council of Nurse Researchers Research Day, Washington, DC.

Menard S, Park M. 1996. *The San Antonio biethnic children's blood pressure study, grades 9-12*. Presented at the Congress of the Association of Operating Room Nurses, Dallas, TX.

Park M, Menard S. 1998. *Pediatric blood pressure standards by circumference-based blood pressure cuff*. Presented at the 42nd Annual Meeting of the American College of Cardiology, Atlanta, GA.

Park M, Menard S. 1995. *Normative oscillometric blood pressure levels in children, kindergarten through 8th grade: The San Antonio biethnic children's blood pressure study*. Presented at the Tenth Scientific Meeting of the American Society of Hypertension, New York, NY.

Park M, Menard S. 1995. *Normative oscillometric blood pressure levels in children, kindergarten through 8th grade: The San Antonio biethnic children's blood pressure study*. Presented at the Tenth Scientific Meeting of the American Society of Hypertension, New York, NY.

Park M, Menard S. 1995. *Oscillometric and auscultatory blood pressure readings are not interchangeable in children*. Presented at the Tenth Scientific Meeting of the American Society of Hypertension, New York, NY.

Park M, Menard S. 1995. *The San Antonio biethnic children's blood pressure study: Preliminary results children*. Presented at the Congress of the Association of Operating Room Nurses, Atlanta, GA.

higher BP levels in white children than AA children, and still other studies showed no differences between white and black children and adolescents. Studies that compared MA and AA children are relatively few. Some studies showed higher BP levels in AA children than in MA children and others showed no difference in BP levels between these two ethnic groups. One study showed BP levels to be higher in MA than in AA children. Diverse methodology used in different studies, including limited age groups studied, may be the major cause of the differences among the reports. A recent report of meta-analysis of previously published data suggests that BP levels of black children and adolescents, especially females, are higher than in other racial groups, but this analysis does not show whether a significant part of the difference is related to the differences in body weight or other measures of body size.

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2. Oscillometric (OSC) findings: No important differences in OSC BP levels were found with the order of the BP method used. Systolic pressure (SP) levels were most closely correlated with weight ($r=0.639$ for boys and $r = 0.500$ for girls) followed by height ($r = 0.594$ for boys and $r = 0.477$ for girls) and age ($r = 0.559$ for boys and $r = 0.418$ for girls). No consistent ethnic differences in SP were found in subjects 5 through 13 years of age. At ages 14 to 15, AA and NHW girls' SPs became significantly ($P<0.05$) higher (3-4 mm Hg) than those from MA girls. No ethnic difference was found for boys. Significant ($P<0.05$) gender difference in SP was present in subjects between 13 and 17 years, with higher SP in boys than in girls (up to 11 mm Hg). Since the differences in SP levels were not consistently different or clinically important among the ethnic groups, BP data were pooled together and normative percentile values developed for boys and girls. OSC SP was 9 to 11 mm Hg higher than AUS SP throughout the age groups studied. OSC DP was 1-4 mm Hg lower than K4 DP and about 4-5 mm Hg higher than K5 DP.

3. Anthropometric findings: No consistent ethnic differences were found in weight, although AA preadolescent boys and girls showed a tendency to be heavier than MA and NHW children did. AA and NHW boys and girls showed a tendency to be taller than MA counterparts, frequently reaching statistical significance ($P<0.05$) throughout the ages studied. Between ages of 13 and 17 years, AA and NHW boys and girls were often significantly ($P<0.05$) taller than their MA counterpart ($P<0.05$). The BMI values of MA boys were almost consistently, significantly ($P<0.05$) larger than NHW boys and showed a tendency to be larger than AA boys, beginning as early as age 6 and continuing through age 17. For girls, a similar ethnic difference was noted as in boys, although rarely significant, throughout the ages studied, with the smallest BMI seen in NHW girls. No consistent significant ethnic differences were present in the triceps skinfold thickness for both boys and girls. Unlike the triceps skinfold, the subscapular skinfold remained more or less stable for boys whereas it showed a small increase in girls between ages of 10 and 17. The subscapular skinfold thickness for MA boys were significantly ($P<0.05$) larger than that for NHW boys starting as early as 8 years of age and continuing till late adolescence. MA girls showed the largest subscapular skinfold thickness.

4. Nutritional and activity findings: NHW boys and girls reported a tendency for a larger caloric intake (kcal/kg) than MA and AA counterparts, occasionally becoming significant ($P<0.05$), but caloric values were the lowest in 15-17 year old NHW girls. Preadolescent AA boys and girls had higher %CHO than other ethnic groups. Percent fat intake was lowest in AA girls. No gender difference was found for %CHO and fat intake. Cholesterol intake was larger in MA and AA children than in NHW children. Boys' cholesterol intake was larger than girls' were, especially in MA and NHW subjects.

AA and MA boys and girls reported significantly longer hours of television (TV) viewing than NHW counterparts. 15% to 25% of AA and MA boys and girls 11 to 17 years old reported spending 4 hours watching TV, while only 5-6% of NHW counterparts reporting the same. AA boys and girls reported more organized sports hours (active hours) than other ethnic groups, with MA subjects reporting the shortest active hours.

Recommendations

This study provides normative auscultatory blood pressures using a blood pressure cuff 45-50% of the circumference of the arm for children ages 5-17 years in three ethnic groups. Additional testing of oscillometric devices must be completed before normative data obtained can be published. This study also shows those blood pressures obtained by auscultatory and oscillometric devices cannot be interchanged. Additional research should be done among African-American children, as the numbers from this study were not as large as needed to generalize.

The most important findings from this study show that children are becoming heavier and less active (as other studies have also shown). It is important that there be additional research in the behavioral and physiological arenas to determine how children become obese and remain obese. Interventions have been for the most part ineffective because the causes of childhood obesity are not fully understood. The problems resulting from obesity and inactivity contribute to most of the high cost chronic health problems in children and adults.

Products To Date

Presentations

Menard S. 1998. *The San Antonio triethnic children's blood pressure study*. Presented at the Third International Nursing Academics Conference, Canberra, Australia.

Menard S. 1997. *The San Antonio biethnic children's blood pressure study*. Presented at the Research Based Nursing Practice, Jyvaskyla, Finland.

Menard S. 1996. *The San Antonio biethnic children's blood pressure study: K-8*. Presented at the National Association of Pediatric Nurse Associates/Practitioners Annual Conference, San Diego, CA.

Menard S. 1995. *The San Antonio biethnic children's blood pressure study: Preliminary results*. Presented at the Research Conference of the Brooke Army Medical Center, San Antonio, TX.

The purpose of the investigation was (1) to study health and development of Puerto Rican children growing up in the mainland of the United States from a normative rather than a deficit model approach, utilizing culturally appropriate theoretical models of development and health; (2) to study the "social context" of health as the relationship among family variables (SES, family composition, proficiency in English) and especially characteristics of the primary caregiver (depression, anxiety, fear of discrimination) and the child's health outcomes; (3) to study the effects of racism, discrimination and prejudice on the children's health; (4) to examine the validity of existing instruments in this population and to develop new ones when needed; and (5) to carry out this study with Hispanic professionals and personnel at all levels of involvement in the research.

Study Design and Methods

The research was grounded in a cultural-ecological framework, adapted from Bronfenbrenner's ecological approach and Ogbu's cultural-ecological model to the changing realities of minority cultures.

The Social Context of Puerto Rican Child Health and Growth Study was a prospective, longitudinal study of the physical and mental health of Puerto Rican children living on the mainland of the United States, carried out by a multi-disciplinary and multi-racial/ethnic team of researchers. The study followed 291 boys and girls (in grades 1 through 3 at the starting point of the study) and their primary caregivers from three socioeconomic strata (SES) for three consecutive years, 199~1998. The data were gathered through face-to-face interviews with the children and their primary caregivers in the language of their choice (English or Spanish).

The sample was recruited mainly through the Boston elementary school system, both public and parochial. At the end of the recruitment period we had 291 families with which to begin the study. Of these families we retained 93% between the first and second wave, and 95% between the second and third wave of data collection, completing the study with 257 families. The sample was similar to the national Puerto Rican mainland population in household composition and economic level.

With the research objectives in mind, we tested the following hypotheses:

In this report, we use the terms Hispanic and Latino interchangeably. In the greater Boston area, where the research was carried out, both terms are frequently used, although the better educated, Spanish-speaking groups tend to prefer Latino to Hispanic.

Standard Model Hypothesis:

Poverty is positively related to poor health outcomes. Poverty was operationalized by level of income, household items, government assistance. Health outcomes were operationalized as incidence of chronic disease, and mental health. **Paradox Hypothesis:**

The majority of Latino children in the U.S.A. live in poverty. However, unlike other poor children, among Latino children there is no consistent association between poverty and poor health. **Cultural Model Hypothesis:**

The closer the family unit is to Puerto Rican culture, the better will be the child's health outcomes. We operationalized the family's closeness to the Puerto Rican culture as (1) the nativity of the parents and the child; (2) Spanish spoken in the home; (3) the caregiver's pride in Puerto Rican culture; (4) the desire to raise the child as Puerto Rican; (5) social support available to the child by number of adults who played a major role in raising the child, and the child being raised with a religion.

We hypothesized that both cultural values and social support are positively correlated with the mother's mental health, which is in turn positively related to the child's health outcomes.

We also postulated that children's experiences with and caregivers' worry about discrimination are negatively associated with health outcomes.

Findings

We created three new instruments: The Color of My Skin, an index to study children's internal perception of their skin color and satisfaction with it; a scale to measure Self-esteem; and an index to study Ethnic Identity and experience with Discrimination in which options for choosing one or multiple identities are given.

We found that in our sample there was no "revolving door" migration. Although as a whole the families were recent migrants, once they came to the mainland they settled here.

The majority of the children were the product of a normal pregnancy and were delivered by a physician in a hospital. The mothers had been followed in a clinic from the first trimester of pregnancy, they consumed less drugs and alcohol than the

national averages but smoked more. Fifty eight percent were in their twenties and 19.5% in their thirties at the time of the birth of the index child. The low-birthweight rate was 8.4% which is lower than the Puerto Rican National sample but higher than other Latino subgroups.

The mothers reported that their children were in good general health (90%). Their only concern was small size and low weight (45%). This perception contrasts greatly with their reporting a high incidence of chronic medical conditions on a number of questions that were also employed in the questionnaire, following the National Health Interview Survey of 1996. In this assessment our sample compared unfavorably to the sample of White, Hispanic and Black children of the same age in the National Survey. Our sample had only 5.5% of uninsured children during the first year of data collection and 2.9% and 2.7% during the second and third years while the Census of 1995 reports 26.8% of uninsured Hispanic children under the age of 18 years.

The majority of the children identified themselves as Puerto Ricans either as only Puerto Ricans or a combination of Hispanic, Americans and Puerto Ricans. Their identification was not related to the parents' place of birth but it was related to the child's place of birth and their caregiver's ethnic identification. As the children matured there was a trend towards multiple rather than single identifications. Eleven percent in the first and second year and 9% in the third had experienced discrimination due to their ethnicity. It is interesting to note that mothers reported a higher experience with discrimination, but more important is their worry about being discriminated against (discrimination anxiety) and the small but significant negative effect on the children's academic self-image.

The majority of the children chose light brown as the color of their skin and 96% liked their color and were satisfied with it. All children reported high self-esteem and there was no association between self-esteem and the chosen skin color. Only the children who wanted to change color had a significantly lower self-esteem. There was a 68% agreement between the interviewer's external rating of the child's color and the child's internal rating.

The children's self-rated self-esteem was consistently high during the three years (4.4, 4.5 and 4.5) on a Likert-type scale of 1 to 5. The depression scores were consistently low (1.73, 1.59 and 1.48 over the three years). The children manifested that they felt higher academic stress than any other type of stress during the three years. The caregivers' assessment of their children's behavioral problems using Conners Parent Rating Scale was very low. Impulsive hyperactivity was the only high one in Waves one and two.

In summary, our sample consisted of a group of emotionally healthy children with poor physical health as compared with other samples.

The Standard Model Hypothesis is supported by the fact that our sample consisted of children living in poverty who are physically ill. Specifically, we found a significant relationship between the family receiving government assistance and the child's anemia, family income and diarrhea and allergies, and receiving government assistance and asthma. Conversely, regarding mental health there is no association of mental or behavioral problems and poverty, which confirms the Paradox Hypothesis.

The Cultural Model Hypothesis was supported by the fact that the stress of being Puerto Rican in the mothers can lead to negative mental health outcomes in the children, that Puerto Rican culture acts as a protective factor, and by the fact that acculturation is negatively correlated with the mother's mental health which in turn is positively correlated with the child's mental health. These associations, however, were weak.

Recommendations

Our results highlight the need for public health programs to improve the living conditions of the poor and thus lead to better health outcomes: nutrition, environmental sanitation, adequate housing. Health education programs need to be directly geared toward the Puerto Rican population to raise awareness of good health habits, the dangers of secondary smoke exposure to children, preventive measures for infectious diseases, and good nutrition.

A new study, with a larger population in a different geographic area, should be conducted to replicate our outcomes, and to apply the new measures to a similar population. Most importantly, the epidemiologic paradox should be tested, and the causes for the puzzling problem as to why Puerto Ricans, as opposed to other Latino subgroups, do not follow the paradox regarding physical health, should be further explained from a genetic, sanitary, medical access and medical service use, cultural and environmental perspective.

Products To Date

Presentations

- Alarcon O. 1999. *Ethnic identity of Puerto Rican children raised in the mainland*. Presented at the Biennial Meeting of the Society for Research in Child Development, Albuquerque, NM.
- Alarcon O. 1997. *The color of my skin*. Presented at the American Psychological Association, Chicago, IL.
- Alarcon O. 1996. *Risk-taking behaviors among Puerto Rican adolescents*. Presented at the American Psychological Association, A Women's Health Conference, Washington, DC.
- Alarcon O. 1995. *Social context of Puerto Rican child health and growth*. Presented at the American Psychiatric Association, Miami, FL.
- Alarcon O. 1997. *Social context of Puerto Rican child health and growth*. Presented at the Multicultural Mental Health Research in the 21st Century Symposium, University of Massachusetts Medical Center, Worcester, MA.
- Alarcon O. 1997. *Social context of Puerto Rican child health and growth*. Presented at the Murray Research Center, Radcliffe College, Cambridge, MA.
- Alarcon O. 1996. *Social context of Puerto Rican child health and growth*. Presented at the Department of Psychology and Psychiatry, Children's Hospital (Harvard University), Boston, MA.
- Alarcon O. 1996. *Social context of Puerto Rican child health and growth*. Presented at the meeting of selected projects on Hispanics funded by NICHD and MCHB, Washington, DC.
- Alarcon O. 1996. *Social context of Puerto Rican child health and growth*. Presented at the Mauricio Gaston Institute for Latino Community Development and Public Policy, University of Massachusetts, Boston, MA.
- Alarcon O. 1996. *Social context of Puerto Rican child health and growth*. Presented at the National Meeting of Professionals of Color, Worcester, MA.
- Alarcon O, Erkut S. 1998. *Skin color and self-esteem: The dilemma faced by Puerto Ricans in the mainland USA*. Presented at the Latino Community in the New Millenium: Where We Are Now and Where We Are Going Conference, Mezcla, Wellesley College, , Wellesley, MA.
- Alarcon O, Erkut S, Garcia Coll C, Fields JP. 1998. *Social context of Puerto Rican child health and growth*. Presented at the Head Start's Fourth National Research Conference: Children and Families in an Era of Rapid Change, Washington, DC.
- Alarcon O, Marshall N, Erkut S, Fields J, Garcia Coll C. 1996. *Creating bilingual/bicultural self-esteem, ethnic identity, and perception of skin color measures for Puerto Rican children*. Presented at the American Orthopsychiatry Association, Boston, MA.
- Erkut S. 1999. *Methodology of obtaining and retaining a sample in a disadvantaged population*. Presented at the Biennial Meeting of the Society for Research in Child Development, Albuquerque, NM.
- Erkut S. 1999. *Methodology of obtaining and retaining a sample in a disadvantaged population*. Presented at the Biennial Meeting of the Society for Research in Child Development, Albuquerque, NM.
- Fields JP. 1999. *Puerto Rican parents' fears of racial discrimination: Impact on child socialization*. Presented at the Biennial Meeting of the Society for Research in Child Development, Albuquerque, NM.
- Garcia Coll C. 1997. *Measuring ethnic identity and discrimination among Puerto Rican children*. Presented at the American Psychological Association, Chicago, IL.
- Garcia Coll CT. 1997. *Social context of Puerto Rican youth*. Presented at the Conference on the Status of Urban Youth, Center for the Study of Race and Ethnicity in America, Brown University, Providence, RI.

Scott-Jones D, Garcia Coll C, Alarcon O, Branch C, Cross W, Erkut S, Jarrett R, Johnson D. 1997. *The role of ethnicity/race in development in middle childhood*. Presented at the American Psychological Association, Chicago, IL.

Szalacha LA. 1999. *The development of a self-esteem measure for Puerto Rican children*. Presented at the Biennial Meeting of the Society for Research in Child Development, Albuquerque, NM.

Szalacha LA. 1997. *Self-esteem of Puerto Rican children in the mainland U.S.A.*. Presented at the American Psychological Association, Chicago, IL.

Tropp L. 1997. *The dual-focus approach to creating bilingual measures*. Presented at the American Psychological Association, Chicago, IL.

The main purpose of this study was to address two questions.

1. What is the natural history of the neonatal "sepsis work-up" during the birth hospitalization in an era of widespread maternal intrapartum antibiotic treatment?
2. Which predictors should be employed in evidence-based guidelines suitable for use by clinicians?

Study Design and Methods

Study subjects were identified prospectively using manual and electronic methods. Maternal and neonatal chart and laboratory data were obtained retrospectively using chart review and electronic downloading. Families of study subjects were contacted prospectively by mail and/or phone. On-site research assistants prospectively reviewed nursery logs, laboratory results, and patient records.

Babies born to women who are Kaiser Foundation Health Plan, Inc. (KFHP) members are automatically covered for the first month of life, which permits very high follow-up rates during the immediate neonatal period. We scanned all available KFHP databases, including those tracking out-of-plan use, so as to define whether, during the first week after discharge, study subjects 1) left the KFHP, 2) were rehospitalized; or 3) died. We also contacted all study subjects' families by mail to enquire about these outcomes. If an infant's outcome during the first week after the birth hospitalization could not be ascertained using the above methods, we made an attempt to contact the baby's family by phone. We then reviewed the electronic hospitalization records, laboratory data, and paper records of all babies who were rehospitalized.

The primary outcome of interest was whether or not a newborn had a vertically transmitted bacterial infection. Outcome assignment was based on culture results or clinical factors (e.g., results of physical examinations or chest roentgenograms). To avoid circular reasoning, we did not use CBC results or treatment decisions to define outcome. A culture-proven infection is defined as an infection confirmed by a positive culture from a normally sterile site. A probable infection is one where the clinical course strongly suggested the presence of infection even though cultures were negative or, if positive, could not be regarded as conclusive (e.g., meningitis with only pleocytosis). A possible infection is one where a baby had negative cultures and equivocal clinical findings but where infection could not be excluded. Rehospitalization was defined as admission within 7 days after a baby first went home.

Statistical analysis included calculation of basic descriptive statistics and bivariate analyses. Multivariate analyses were performed after stratification by maternal treatment status. Guideline development included the above plus the use of recursive partitioning (classification and regression trees, CART) to generate output for review by a panel of clinicians.

Population Description and Sampling Plan

We employed the proper denominator, all babies ever evaluated. A baby was considered to have been evaluated for sepsis if a physician suspected the condition and obtained a complete blood count (CBC) and/or blood culture. This definition was independent of either treatment or outcome. Babies were included if they 1) weighed \geq 2000 grams at birth; 2) were born in the hospital at the Kaiser Permanente Hayward, Oakland, Sacramento, San Francisco, Santa Clara, and Walnut Creek facilities between 10/95 through 11/96; 3) were ever evaluated for bacterial infection during the birth hospitalization; and 4) did not meet exclusion criteria. Babies were excluded if 1) a major congenital anomaly was present; 2) the first evaluation was for suspected nosocomial infection; 3) the baby was born outside the hospital; 4) the first evaluation occurred after discharge home; 5) a CBC was performed for other reasons (e.g., jaundice); or 6) the CBC was obtained to evaluate for syphilis, gonorrhea, or human immunodeficiency virus (HIV) infection.

Findings

A total of 19043 birth hospitalizations occurred at the 6 study sites; of these, 2785 (14.6% of live births) met study criteria. We were able to track all but 10 (0.4%) of these infants to one week post discharge. Of the 2785 infants, 2539 (91.2%) were identified as being at risk sepsis by 12 hours of age; 853 (30.6%) received systemic antibiotics; 206 (7.4%) were ventilated; 22 (0.8%) had a positive culture (15 group B streptococcus, 5 E. coli, 2 other; 1 death occurred in this group); 15 (0.5%) had a probable infection (2 deaths occurred in this group); 25 had a possible infection (1 death occurred in this group); and 67 (2.4%) were rehospitalized (2 with group B streptococcus bacteremia). The most common reasons for rehospitalization were jaundice and dehydration/feeding difficulties. Among 679 babies who required supplemental oxygen, 93.1% received such therapy by 12 hours of age, while 89.8% of the

206 who were ventilated had such therapy initiated by 12 hours of age. Maternal fever, chorioamnionitis, low neonatal absolute neutrophil count (ANC) for age, and presence of neonatal clinical signs were associated with infection. There were 1217 infants whose mothers received intrapartum antibiotics and 1568 whose mothers did not. Compared to infants whose mothers were not treated, infants of treated mothers were more likely to be asymptomatic (71.5% vs. 50.9%, $p = 0.001$) and less likely to be critically ill within 6 hours of birth (5.4% vs. 7.5%, $p = 0.021$).

We stratified infants according to maternal treatment status and conducted multivariate analyses. Among infants whose mothers were not treated, maternal chorioamnionitis (adjusted odds ratio [AOR] 2.40, 95% confidence interval [CI], 1.15-5.00), low ANC for age (AOR 2.84, 95% CI 1.50-5.38), and presence of meconium in the amniotic fluid (AOR 2.23, 95% CI, 1.18-4.21) were associated with an increased risk for infection, while initial asymptomatic status was associated with a decreased risk (AOR 0.26, 95% CI 0.11-0.63). Results were similar for infants whose mothers were treated except that chorioamnionitis was not a significant predictor for infection.

We also found that 1) use of epidural anesthesia is associated with a 0.5 F increase in maternal temperature, even after controlling for the presence of chorioamnionitis, 2) published ANC norms misclassify almost half of babies with infections, 3) increased risk of infection is seen when time of rupture of membranes exceeds 12 hours, 4) widespread practice variation exists with respect to maternal and neonatal antibiotic treatment, and 5) there are many missed opportunities for maternal antibiotic prophylaxis.

Recommendations

1. Current guidelines need to be revised in light of these data which highlight the protective effect of maternal intrapartum antibiotics. The best approach to decreasing maternal and neonatal mortality and morbidity due to bacterial infection is to increase the proportion of women who receive appropriate intrapartum antibiotics.
2. Evidence-based approaches should emphasize a) careful clinical assessment in the first 24 hours of age, b) close attention to maternal risk factors, and c) limited use of the CBC.

Products To Date

Abstracts

Escobar GJ, Li DK, Armstrong MA, Gardner NM, Folck BF, Verdi JE, Xiong B. 1999. The neonatal sepsis work-up: A population-based study. *Pediatric Research* 45:268A.

Articles

Escobar GJ. 1999. The neonatal sepsis work-up: Personal reflections on the development of an evidence-based approach toward newborn infections in a managed care organization. *Pediatric* 103:360-373.

Escobar GJ, Li DK, Armstrong MA, Gardner MN, Folck BF, Verdi JE, Xiong B. 2000. Neonatal sepsis work-ups in babies \geq 2000 grams at birth: A population-based study. *Pediatric* 106(2 Pt 1):256-63.

Presentations

Escobar GJ. 1997. *Rule out sepsis: The big baby in the NICU*. Presented at the Redesigning Neonatal Intensive Care for Managed Care Conference, Chicago, IL.

Escobar GJ. 1998. *Rule out sepsis: The big baby in the NICU*. Presented at the Neonatal Intensive Care: Increasing Quality and Decreasing Costs Conference, Boston, MA.

Escobar GJ. 1999. *Watchful waiting vs. antibiotics A.S.A.P.*. Presented at the Kaiser Permanente 15th Annual Neonatal Medicine Symposium, Costa Mesa, CA.

Escobar GJ. 1999. *Neonatal "sepsis work-up": A population study*. Presented at the 26th Research Roundtable, Maternal and

Child Health Bureau, Rockville, MD.

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