



# Research Roundtable Summary



**FIFTEENTH**

in a Series of Seminars

on MCHB-funded

Research Projects

## **A Telephone Educational Intervention for Rural Children with Asthma**

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### About This Series

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

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

### Introduction

Dr. Gontran Lamberty introduced the speakers for the research roundtable. Dr. Murphy is chair and professor of pediatrics at the University of New Mexico School of Medicine. Dr. Murphy's research interests include asthma, cystic fibrosis, and bronchopulmonary dysplasia. She has published extensively in *Pediatrics*, *American Journal of Respiratory and Critical Care Medicine*, *The Journal of Pediatrics*, and *American Review of Respiratory Diseases*. In 1996 and 1997, Dr. Murphy has served as chair of the National Heart, Lung, and Blood Institute's Expert Panel on Guidelines for the Diagnosis and Management of Asthma. She also has served as the chair of the Food and Drug Administration's Pulmonary and Allergy Drugs Advisory Panel. After receiving her medical degree from the University of Kansas School of Medicine, Dr. Murphy completed a pediatric residency at UCLA-Harbor General Hospital and a fellowship in allergy and immunology at the Charles R. Drew Postgraduate Medical School in Los Angeles. Along with Dr. Murphy, Dr. Jean Hanson and Ms. Jodi Lapidus constituted the team responsible for the research study. Jean Hanson, R.N., Ph.D., recently completed her doctorate in health education from the University of New Mexico. She has a special interest in self-efficacy, asthma self-management, and patient and family education. Jodi Lapidus, M.S., is a senior statistician for the Department of Pediatrics at the University of New Mexico School of Medicine. She has a strong interest in public health research, statistical theory, and methodology. She is currently pursuing a doctoral degree in applied statistics.

## Presentation

### *Statement of the Problem*

Children with asthma represent a heterogeneous population that varies in its need for health care services. Unlike congenital anomalies, dysmorphic syndromes, or orthopedic handicaps, asthma is an invisible, episodic, and variable disease. Because of this, children with asthma may be seen as not readily fitting into the “children with special health needs” category. However, the pediatric asthma population represents one of the largest groups fitting the definition of “needing specialized health services.” Asthma, particularly when defined as moderately severe to severe, impacts child and family functioning, school functioning, and health care economics.

Asthma is a leading cause of morbidity in childhood and affects over 2,700,000 children under 18 years of age, as reported in the 1988 National Health Interview Survey. Low income is a significant predictor for sick days and missed school days, and those children living in households below the poverty level have a significantly higher prevalence of asthma than children in higher income households. Pediatric asthma has accounted for 7.3 million days restricted to bed, 10.1 million days missed from school, 12.9 million contacts with doctors, and 200,000 hospitalizations (1.9 million days of hospitalization). Most alarming is evidence that the prevalence of asthma increased 58 percent in 6–11-year-old children during the 1970s. The rate of hospitalization for asthma in children under age 17 increased 4.5 percent per year from 1979 to 1987. The increase in the severity of asthma is of particular concern in terms of child and family adaptation.

Psychological development and family functioning are affected by this asthma morbidity. The disruptive influences on the child have been well-documented and include increased numbers of school absences, low self-esteem, and psychological maladjustment.

Although it was the 11th fastest growing State in the early 1980s, New Mexico is still sparsely populated. New Mexico’s population density is approximately 12 persons per square mile; only 11 of the State’s 33 counties exceed 10 persons per square mile. Thirteen of the 33 counties have population densities of fewer than 5 persons per square mile. These statistics support the fact that New Mexico is largely a rural State. The State has four major racial/ethnic groups: Non-Hispanic whites (50.4 percent), Hispanics (37.5 percent), Native Americans (8.9 percent), and African Americans (2.0 percent). In terms of income, New Mexico ranks 46th in the Nation. In 1990, per capita personal income was \$14,228, which was 24 percent lower than the national figure of \$15,340.

Health care manpower statistics indicate that New Mexico has 1.79 primary care providers for children with moderately severe to severe asthma per 1,000 children; the national average is 2.14 providers per 1,000 children. Rural counties in the State have only 0.56 providers per 1,000 children. Ten counties have no primary care clinic, three counties have no primary care physicians, and two counties have no physicians at all.

Prior to this project, New Mexico’s children with asthma had not been systematically studied. There were no data on hospitalization rates. However, one study in a semirural county documented that 6.5 percent of Hispanic males under age 6 had been diagnosed with asthma. Among boys ages 6–12 and 13–17, 4.2 percent and 10.5 percent, respectively, had asthma. For girls, the range was 2.5–4.5 percent, significantly lower than the rate for boys. The national rate for all children ages 3–7 is 6.7 percent. These data indicate that in New Mexico, the incidence of asthma is approximately 50 cases per 1,000 children, for a total of approximately 25,000 children.

A recent survey investigated the prevalence of asthma in children of the Jemez Tribe, a Native American tribe in New Mexico. Using a respiratory symptom questionnaire completed by parents, researchers found an asthma prevalence of 12.3 percent in this population. This prevalence of childhood asthma was much higher than in recent national surveys. Also, the Jemez study found a strong association with bronchiolitis.

These population and economic factors led to the recognition that New Mexico, as a vastly rural, low-income, and ethnically diverse State, must have identifiable service delivery problems and solutions for children with special health needs. A model was needed to both address the needs inherent in rural and ethnically diverse populations and identify optimal service delivery systems that could be used to provide innovative health care to children and their families.

Children's Medical Services, a division of the State of New Mexico Department of Health and Human Services, has been a progressive and guiding influence on health care for children with special health needs. In 1989, Children's Medical Services expanded its program to cover children with asthma. The services included identifying eligible families, providing case management, financing medications and hospitalization, and providing emergency room and physician office visits. All children with asthma were screened, and those who met the criteria of moderately severe to severe were referred to the University of New Mexico (UNM) Pediatric Pulmonary Center for evaluation and treatment. Children's Medical Services piloted this program in partnership with the UNM Pediatric Pulmonary Center in six rural New Mexico counties in 1989.

The UNM Pediatric Pulmonary Center is the only tertiary care program for asthmatic care and management in the State of New Mexico. It is funded by a Pediatric Pulmonary Center grant from the Maternal and Child Health Bureau and the State of New Mexico. The center consists of an interdisciplinary team of professionals—physicians, nurse specialists, a nutritionist, a social worker, a geneticist, a family counselor, and a clinical pharmacist—who provide state-of-the-art care. Historically, the center has been committed to working with Children's Medical Services on a variety of projects that have enhanced family-centered programs, as well as working with primary care physicians in the continuing management and followup of these children. The association between Children's Medical Services and the UNM Pediatric Pulmonary Center has provided unique strengths with which to evaluate programs for the delivery of care to children with special health needs, particularly asthma.

A recent focus of health behavior research has been the self-management of chronic asthma by children and their families. Self-management programs teach children and their parents effective ways to manage the disease and reduce reliance on the health care system. It was important to determine if such educational self-management programs are effective in a rural population when conducted by a tertiary center in close collaboration and communication with rural primary care physicians. Given the sparse resources and distances to acute care settings in rural areas of New Mexico, it was also important to determine if a self-management program would reduce unnecessary hospital and emergency room utilization and make family/child asthma management more effective.

### *Research Questions or Hypotheses*

The overall question asked in this study was “Does a comprehensive medical plus educational self-management program for children with asthma living in rural communities have an impact on asthma morbidity and family stress as well as on the cost of medical care?”

Specifically, the study tried to determine whether, compared with comprehensive medical care alone, the provision of medical care and a self-management education program would:

1. Reduce asthma morbidity and health care utilization as indicated by improved pulmonary function parameters and fewer emergency room visits, hospitalizations, daily symptoms, and school and parent work days missed;
2. Reduce family stress, as measured by the Parenting Stress Index;
3. Enhance self-management and self-efficacy, as measured by a self-report in a structured interview;

4. Enhance self-reported satisfaction with delivery of asthma-related health care services, both in the tertiary and primary care areas; and
5. Reduce hospitalization and emergency room costs without decreasing the cost of providing asthma services overall.

### *Study Design, Methods, and Population Description*

To address these questions, two groups of children with asthma were studied. One received comprehensive medical care (CMC) consistent with Guidelines for the Care of Children with Chronic Lung Disease and the National Institutes of Health's Guidelines for the Diagnosis and Management of Asthma. This group also received individual education according to a standardized protocol delivered by a nurse educator. The other group received the same medical services plus a structured asthma self-management education program and periodic phone followup by a nurse educator (CMC-Plus). To qualify for the study, the child was required to have a diagnosis of moderately severe to severe asthma. Children were referred to Children's Medical Services by local physicians, school nurses, relatives, and word of mouth. If the family met the agency's financial guidelines, a clinic visit was scheduled at the UNM Pediatric Specialty Clinic. Medical eligibility was met if the child met any one of the following criteria: Two or more hospitalizations per year for asthma; 4 or more emergency or urgent care visits for asthma in 1 year; daily use for 3 months of 2 or more asthma medications; interference with daily activities (i.e., more than 10 percent missed school days for asthma as determined by the primary care physician); abnormal pulmonary function (test done at UNM with percent predicted FEV1<75 percent or FEF50<50 percent of normal prior to bronchodilator); or positive methacholine challenge in the moderate to severe range.

Children ages 6 months–21 years were initially included, but the lower age limit was increased to 2 years after it was determined that diagnosing asthma in children less than 2 years of age was difficult. Children with severe underlying pulmonary or medical conditions—such as bronchopulmonary dysplasia, cystic fibrosis, or heart disease—were excluded from the research study. A child was not entered into the study if the family had previously received extensive asthma education, including: (1) Attendance at the regular pulmonary clinic, (2) evaluation at National Jewish Hospital, or (3) previous enrollment of a sibling.

Thirty-two of the 33 counties in New Mexico were matched by population and percentage of Hispanic residents based on the 1989 New Mexico Selected Health Statistics. One county in each pair was then randomly assigned to the CMC group, and the other county was assigned to the CMC-Plus group. Bernalillo County, which includes Albuquerque, was not randomized to either the CMC or the CMC-Plus group, because there was no adequately sized county match in the State. Children's Medical Services did not cover costs of asthma care in this county. Children's Medical Services workers in 20 of the 33 New Mexico counties enrolled moderately severe to severe asthma patients in the project between 1990 and 1992.

The CMC group received individual education by a trained nurse educator during the clinic visits. *Guidelines for the Diagnosis and Management of Asthma* were used in formulating the medical and patient education plan. All families received *Facts About Asthma*, a National Heart, Lung and Blood Institute publication, and various handouts developed by the Pediatric Pulmonary Center on the different asthma medications and use of equipment and devices. The nurse educators spent approximately 30–45 minutes with the families at the first visit and 10–15 minutes at subsequent visits.

Members of the CMC-Plus group received individual education and group education during their clinic visits. The Open Airways Asthma Self-Management Program was utilized and modified into four sessions. Families attended two classes during the initial visit and two classes at the 1-month followup visit. They also received Open Airways materials to take home and additional handouts

developed by the Pediatric Pulmonary Center. Subsequent visits included a review at 6 months, a problem-solving session based on scenarios at 1 year, and a “Kids on the Block” puppet show at 18 months. At the final 2-year visit, there was no group class, and the family received a certificate and a token gift.

As part of the educational intervention, the CMC-Plus families received scheduled phone calls from a nurse educator. The purpose of these phone calls was to assess the medical status of the child and family understanding of the asthma treatment plan. In addition, education was reinforced, and any problems were addressed. Calls were made at 3–4 days after the initial visit and at 2 months, 4 months, 8 months, 14 months, and 20 months. The first phone call focused on whether the family was able to obtain the medications and equipment, and, if not, why. The family was advised on how to proceed, and any questions were answered. The action plan was reviewed at each phone call, and families were reminded to see their primary care doctor for routine visits.

The Basic Asthma Questionnaire is an instrument that was specifically developed for use in this project. A number of evaluation tools used in other asthma intervention programs were incorporated after pilot testing, including items related to demographics, use of alternative medicines, and language preference. The questionnaire was administered by nurse educators or trained interviewers in a standardized manner—usually by phone—prior to the clinic visit. The medical history and followup interview was developed for the project in order to obtain additional information about morbidity and health status. The physicians collected this information during the clinic visit.

The Parenting Stress Index (PSI) is a questionnaire designed to measure stress in parenting by assessing child characteristics, parental characteristics, family context, and life stress. This instrument was chosen because it is well-established and was designed for postmeasurements of intervention effectiveness. The PSI contains statements such as “My child gets upset easily over the smallest thing,” and “Most times, I feel that my child likes me and wants to be close to me.” Parents respond to these statements on a Likert scale.

There are 2 versions of the PSI: A long form (120 items) and a short form (36 items), both of which were utilized. All the short-form items are extracted from the long form. The long-form PSI score can be divided into 13 subscale scores, 6 relating to child stress (child domain) and 7 relating to parental stress (parent domain). The child domain represents characteristics of children that are stressful to parents and may be associated with behavioral or other developmental problems. The short-form PSI score can be divided into 3 subscale scores: Difficult child, parental distress, and parent-child dysfunctional interaction. The difficult child subscale is associated with the child’s self-regulatory capacity and contains items from the child adaptability, demandingness, and mood subscales of the long form. The parental distress subscale contains many items from the parental depression subscale, plus a few others from the parent domain of the long form. The parent-child dysfunctional interaction subscale measures the sense that the parent does not derive satisfaction from interaction with the child.

The decision to vary the PSI forms was based on parents’ reluctance to fill out the long form due to its length. The reliability of the short-form PSI was tested in the population. As a result, it was decided to continue to use the long-form PSI at baseline and at the 2-year followup to obtain the most detailed preintervention and postintervention data. The short form was utilized at the 6-month and 1-year followups. Since all the short-form questions were extracted from the long form, short-form scores were collected at all four followups. The forms were mailed to parents approximately 1 month prior to their clinic visit and were self-administered. If parents forgot their form, another was self-administered at the UNM clinic visit.

Parental self-management skills and self-efficacy items measuring self-management skills were extracted from the Basic Asthma Questionnaire. Many of the items measuring self-management skills were adapted from the Open Airways evaluation tool and used with permission. They were

modified after lengthy discussions with the developers of the instrument, Drs. Clark and Evans.

Pulmonary function testing was performed on children ages 5 and older with spirometry before and after use of a bronchodilator. This was done at baseline and all subsequent visits. Predicted values for each of the spirometry measures were calculated with National Jewish Hospital's published equations based on patients' age and height. The percent predicted for each measure was then determined. Methacholine challenge testing was performed at baseline and at the 1- and 2-year visits. Provocative concentration of methacholine causing a drop in FEV1 of 20 percent (PC20) and the log of the dose-response slope (LDRS) were calculated from raw methacholine data. All raw spirometry and methacholine challenge data were downloaded from the pulmonary function test computer and merged with the project data base for analysis.

It was hypothesized that in both groups, self-management skills would increase over baseline, but the CMC-Plus group would attain more skills than the CMC group. To test this hypothesis, the nurse educators and physicians selected certain self-management skills questions from the Basic Asthma Questionnaire. The information solicited was self-reported behavior by the parent, and the questions were asked in a nonprobing manner. Usually, the same parent responded to the questionnaire at each time point.

Twelve items were selected from the questionnaire as representative of self-management skills. They were grouped into two categories of six items each, as follows:

1. Episodic skills: The parent gives asthma medicine, checks peak flow, gives extra asthma medicine during an episode, knows to use 3–4 treatments within 1–1.5 hours during an asthma episode, goes to the emergency room (ER) if increased medicine is not helping, and goes to the ER if peak flow has decreased;
2. Prevention skills: The patient regularly uses the prescribed anti-inflammatory medicine, regularly uses routing medicine, increases medicine with a cold, increases medicine before exercise, increases medicine before exposure to a known trigger, and avoids known triggers.

The baseline data were analyzed and a score was obtained for each parent by assigning 1 point for each correct response (thus a parent could score between 0 and 12 points). In addition, factor analyses were performed on all 12 components, and the factors' reliability was tested.

The impact of the project on parents' asthma self-management skills was evaluated by examining a 10-point skills score, as well as the 12 individual self-management skills. Parental self-efficacy was measured via the following four items:

1. How sure are you that you can prevent your child from having asthma symptoms such as wheezing or coughing?
2. If your child starts to have asthma symptoms such as wheezing or coughing, how sure are you that you can keep the asthma from getting worse?
3. How sure are you that your child can prevent asthma symptoms such as wheezing or coughing all by him/herself?
4. If your child starts to have asthma symptoms such as wheezing or coughing, how sure are you that he/she can keep the asthma from getting worse all by him/herself?

Approximately 50 families from the study participated in several focus groups at their final 2-year visit. The program's strengths and weaknesses were explored. Overall, the families reported that the program was very beneficial, and they particularly liked the education. They disliked being at the clinic all day, especially when they had to travel long distances to get home afterwards. They also disliked and did not see the relevance of the PSI form. Logistically, it became very difficult to continue these focus groups. A decision was made to drop the focus groups, because the necessary information to develop a standardized exit questionnaire was already gained. The information obtained through the focus groups allowed the development of the Satisfaction with Care instrument.

A customized data base was developed for this project to keep track of patient clinic appointments, questionnaires, telephone followup calls, and local doctor visits. It was written as a customized application in Dbase IV, so that users could follow the instructions on the screen to enter and retrieve data specific to this project. The research portion of the system allowed direct entry of all project questionnaires and forms, with extensive edit-checking mechanisms built in to avoid data entry error. The data base was housed on the file server of the pulmonary division's local area network so that multiple project staff could access the information simultaneously. Programs calculated scores where applicable. To further ensure the integrity of the data, extensive edit checking in the system was supplemented with periodic random chart reviews.

Patients' information was entered into this data base upon their referral from Children's Medical Services, and each patient was assigned a unique project identification number. Subsequently, the system allowed scheduling, canceling, and rescheduling of patients for all UNM clinics, as well as outreach clinic visits. For each patient at each visit, status information was entered for all applicable questionnaires and forms. Information about phone followups and local physician visits was also collected at appropriate time points. To keep missing data to a minimum, another customized report was run regularly listing all unknown information. This information was then found and entered into the system. Overall sample size, race/ethnicity, county enrollment, and questionnaire completion rates were printed.

### *Research Findings*

The mean age of the subjects was 8.5 years for the combined sample. Thirty-six percent of the subjects were female, and 64 percent were male. Race/ethnicity was 61 percent Hispanic, 28 percent non-Hispanic white, 8 percent Native American, and 4 percent other. The average age of onset of asthma was 3.2 years. The average family size was 4.7 people. Eighty percent of the mothers were high-school graduates, and 37 percent had attended trade school, junior college, or college. Forty-eight percent of the mothers were homemakers or unemployed. Seventy percent of the fathers were high-school graduates, and 35 percent had attended college (trade, junior college, or college). Forty percent of the families reported earning less than \$10,000 per year, while 39 percent reported earning between \$10,000 and \$20,000 per year. Although 73 percent of the families reported living within city or town limits, a number of families had to travel to receive their medical care. Most families (66 percent) reported that they received regular asthma care fairly close to home (i.e., 10 miles or less), but 14 percent reported having to travel 30 miles or more to get care, and 4 families had to travel more than 75 miles to a hospital. CMC-Plus families reported being farther from a hospital than CMC families (18.2 miles versus 10.9 miles). Forty-seven percent of the families had a member who currently smoked in the home. The CMC and CMC-Plus groups were comparable on all the baseline demographic data except for the patient's age and the education of the father. The CMC patients were significantly older than the CMC-Plus patients, with a mean age of 9.4 years and 7.2 years, respectively. CMC patients' fathers had received significantly less formal education; 37 percent had not completed high school, whereas only 19 percent of CMC-Plus patients' fathers had not completed high school.

Asthma morbidity and health care utilization decreased significantly in both groups, as measured by reported hospitalizations, ER visits, symptoms, school days missed, and parent work days missed. This decrease was observed by 6 months, with very little further decrease later in the project period. This effect was sustained for 2 years.

There were no significant differences between the two groups' results. Therefore, structured self-management education and phone followup by nurse educators did not have a measurable impact on morbidity and health care utilization over individual education alone. With the exception of age, no differences in race/ethnicity, income, or any other demographic variables were observed. Children 4 years of age and younger were hospitalized more frequently, and parents reported more symptoms for children 5 years and older.

Pulmonary function was measured by percent predicted for FVC, FEV1, and FEF 25–75 percent. None of the lung function measurements improved significantly over time with the exception of FVC, but the small increase observed in the FVC is not clinically significant. There was no significant difference between the two groups for any of the measures with the exception of the FEF 25–75 percent, which was higher at most time points for the CMC group. Methacholine challenge parameters did not change over the project period, nor were there any differences between groups.

In terms of family stress, as measured by the PSI, the CMC group did show an overall reduction in the total stress score. This reduction may have occurred because of the high baseline score in this group. The mean score for the CMC-Plus group did not change over time.

Self-management skills significantly increased over time. The CMC-Plus group scored marginally higher than the CMC group at all time points until the 2-year visit. In both groups, the largest increase in self-management skills occurred in the first 6 months. Parental self-efficacy increased significantly over time in both groups, and although not statistically significant, the CMC-Plus group score appeared to be trending higher than the CMC group score. Parents felt more confident in treating an asthma episode than in preventing an episode.

The CMC-Plus group expressed overall satisfaction with the program, but the only individual variable related to satisfaction that was different between the groups was the local physicians' knowledge about asthma. The CMC group believed their physicians' knowledge increased more.

Due to the complexity of analyzing the data, cost of care is still under analysis. This State-funded program was successful in identifying and providing asthma medical care and education to children with moderately severe to severe asthma and their families in a rural State with a large minority population. In both groups, morbidity decreased and parents increased their reported self-management skills. Structured group asthma education and nurse educator phone followup is expensive and very difficult to provide in a rural medical setting. Since the benefit of group education/phone followup over individual patient education was small, the extra time and effort required do not seem warranted. In addition, the maximal reduction in morbidity and increase in self-management skills by parents was attained by 6 months, so a longer intervention may not have a further impact. In this era of health care reform, it is important to determine if the impact on asthma morbidity and self-management skills shown in this project can be achieved and maintained with a shorter, less complex intervention.

## Discussion

Discussion questions from attendees addressed the PSI and the process of identifying the most cost-effective intervention.

Dr. Murphy stated that this project has demonstrated that a State agency whose mission is to provide services for chronically ill children can provide asthma services in collaboration with a university health care delivery system. This collaborative project began providing financial coverage and case management in 1990. This program has received more support from both staff and families throughout New Mexico than any other CMS program.

As health care reform is debated, Dr. Murphy and the project families feel that the money spent on preventive medicine and visits to asthma specialists will help decrease use of health care resources. This needs to be considered by those making policy for children with chronic health conditions.

## Publications

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