

# Summary of the Capitol Hill Breakfast Briefing on Disease Management and Genetics

September 24, 1997

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The FRIENDS of the NINR held the third breakfast of the series of breakfast briefings this year on September 24, 1997. The topic was disease management and genetics. FRIENDS, an independent, non-profit membership organization, supports the NINR by promoting public awareness of the role of nursing research in advancing health care practice in the United States. Those attending the briefing included Congressional members and staff, nurse researchers and administrators, and members of public and private organizations having a special interest in the topic.

Colleen Conway-Welch, PhD, RN, FAAN, President of FRIENDS and Dean of Vanderbilt University School of Nursing, provided introductory remarks that included recognizing Dick Thompson, Vice President of Government Affairs of Bristol-Myers Squibb, which hosted the breakfast. She also acknowledged the cosponsorship of the event by Senators Daniel Inouye (D-HI) and William Frist (R-TN). Laurie Turpin of Senator Inouye's staff expressed his regrets at being unable to attend and stressed his long-standing support of nursing. She said he was most proud of his legislative efforts leading to the creation of the National Center for Nursing Research at NIH, and later to the establishment of the National Institute of Nursing Research.

Patricia A. Grady, PhD, RN, FAAN, Director of the National Institute of Nursing Research, opened the scientific discussion by noting that recent, multiple scientific and technological advances are bringing the Nation to a new era in health care. At the forefront of these breakthroughs is increased knowledge about the genetic basis of diseases and conditions. It is likely that over the next decade, genetic therapies will be improved for use in the treatment of human disease. These and other advances are transforming health care in this country and are changing the expectations and opportunities for nurses in the health care system. Dr. Grady also pointed out that 90% of disease-related genetic mutations may indicate a predisposition to a disease. This provides the opportunity to modify risk factors that may prevent or forestall the occurrence of the disease. Nursing research is well positioned to pave the way for intervention strategies to achieve these goals.

In providing examples of current nursing research supported by the NINR, Dr. Grady mentioned:

- A program to improve dietary management of high cholesterol levels run by public health nurses in rural county health departments;
- Management of severe urinary incontinence in older women living at home in a rural community;
- Control of diabetes in teens by combining intensive insulin therapy with a strengthening of social skills that promotes good diets and healthy social lives.

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## THE RESEARCH

Nurse Prenatal Home Care for High Risk Pregnant Women: Outcome and Cost. Dorothy Brooten, PhD, RN, FAAN, Associate Dean for Research and Graduate Studies, The John Burry Jr. Professor of Nursing at The Frances Payne Bolton School of Nursing, Case Western Reserve University, Cleveland, Ohio

Dr. Brooten stated that the United States currently ranks 22nd in infant mortality among industrialized countries, attributable mainly to the high number of low birth weight (LBW) babies. LBW babies are high cost babies who have many more emergencies and acute care episodes in the first year of life. Key questions faced by the family and health care professionals are: Will the baby live? And if so, what quality of life will the baby have?

Dr. Brooten and colleagues developed a model of transitional care which allowed patients to be discharged early from the hospital. The model has been tested on a number of different populations. She discussed her current research to reduce LBW in high risk childbearing women through use of transitional care. Her study consisted of two groups. Eighty-six women in one group received the usual prenatal care, which for the patient often involves a bus ride and a 3.5 hour wait, followed by 5 minutes with a physician. For the other group consisting of 85 women receiving the special intervention, half the usual prenatal care was substituted with care in the women's homes, provided by Masters Degree prepared perinatal nurses. The nurses' care included monitoring the women's physical and psychological well being, coping skills and support systems, as well as monitoring the health of the fetus. The nurses also telephoned the women often and were available by telephone daily to answer questions and concerns.

Preliminary findings from the study indicate that in the intervention group there were:

- fewer infant deaths
- fewer preterm births
- several hundred days of hospitalization saved
- reports of significantly greater satisfaction with care

Improving Care for Young Underserved Urban Black Men with High Blood Pressure. Martha N. Hill, PhD, RN, FAAN, Professor and Director of the Center for Nursing Research, The Johns Hopkins University School of Nursing

Cardiovascular diseases are the greatest factor contributing to the mortality gap between African-Americans and Caucasians. High blood pressure, which is estimated to cost \$30.0 billion in 1997, is the most prevalent risk factor in African-Americans. Young African-American men have the most severe high blood pressure and complications, yet they have the poorest rates of awareness, treatment and control.

Dr. Hill described her 12-month study of 204 young African-American men, a population difficult to attract to health research projects. The men are typically not in health care clinics, for example, where recruitment is easier. Emergency room contacts and outreach in the community, using ethnic community members to spread the word, proved to be effective recruitment tools for Dr. Hill. Ninety-one percent of the men remained with the research project for the entire 12 months.

The young men were divided into two groups one receiving high blood pressure education and referral to medical care; the other receiving the same service, plus closer follow-up by telephone and a home visit by a community health worker. At the end of 12 months, there was no improvement for either group in obtaining or remaining in care, or in control of high blood pressure.

The second stage of the project, however, was a pilot study in which a nurse practitioner and community health worker team provided free care and medication for 18 men for 12 weeks. The intensive intervention was very effective, controlling high blood pressure in two-thirds of the men. This interdisciplinary team approach is now being evaluated in an expanded two-year trial, also supported by NINR, involving over 250 young underserved African-American men.

Dr. Hill's research results will be published in the American Journal of Hypertension.

## CHALLENGES

Below are some of the challenges for nursing research linked to the scientific presentations discussed at the breakfast briefing:

- Technological advances -- Nursing research investigators must continue to develop and test strategies that ensure public understanding and effective use of technological advances, such as genetics. A productive line of inquiry, for example, would be genetic screening. Most mutated genes related to disease indicate a predisposition that may be sparked by environmental conditions or behavioral habits to produce the disease. Genetic screening that reveals these mutations provides the opportunity to forestall or prevent disease, but currently little is known about which lifestyle changes or environmental factors are influential, and which modifications will produce the best results to maintain health.
- Transitional care -- Nursing research has much to offer in an era where improvement of health care quality and reduction of health care costs are twin national goals. Progress is already evident in studies like the transitional care model described above by Dr. Brooten. The increased use of managed care, paralleled by heightened public scrutiny of this type of healthcare provider, produce ample opportunities for creative, cost-effective interventions, developed by nursing research, that emphasize prevention, health promotion, and symptom management.
- Ethnically and culturally sensitive research -- Current and anticipated research advances in treatments and prevention techniques are truly impressive, yet populations particularly vulnerable to certain diseases are not receiving the benefits of therapeutic remedies, such as the young African-American men described by Dr. Hill. A strong emphasis of nursing research is support for ethnically and culturally relevant studies and interventions. This is a challenge of special urgency in light of the projected trends for dramatic growth in the Nation's minority and older populations, groups who are at special risk for illness.