

Summary of the Capitol Hill Breakfast Briefing on

Aid in Decision Making and Management of Cancer

March 17, 1999

The FRIENDS of the National Institute of Nursing Research held its first of three breakfast briefings this year on March 17, 1999. The topic was Aid in Decision Making and Management of Cancer. 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 Members of Congress, Congressional staff, nurse researchers and administrators, and members of public and private organizations with a special interest in the topic.

Diane McGivern, PhD, RN, FAAN, head of the Division of Nursing, New York University, and the new President of FRIENDS of the NINR, provided welcoming remarks and thanked the Congressional sponsor of the event, Representative Louise Slaughter (D-NY).

Patricia A. Grady, PhD, RN, FAAN, Director of the NINR, highlighted the Institute's comprehensive research portfolio that addresses family caregivers and chronic illness, including cancer and noted that two NINR-supported centers around the country are predominantly focused on management of symptoms of cancer. These centers are located at the University of California, San Francisco, and the University of Pennsylvania.

In highlighting NINR's cancer research portfolio, Dr. Grady mentioned studies of improving patient adherence to cancer treatment regimens necessary to prolong life. She provided examples, including studies to prevent and manage nausea during chemotherapy, so that interventions can be provided to ward off difficult treatment side effects and improve adherence to treatment. Dr. Grady also cited another important NINR research area -- genetic screening for cancer, decision-making, and coping with possible negative results. She also mentioned research on the common cancer symptom of fatigue and referred to the study of "attention fatigue" commonly seen following surgical treatment. Under study are interventions to restore attention in women treated for breast cancer. Since early detection of cancer is key to effective treatment, NINR-supported researchers are also studying ways to improve the timely use of cancer screening tests, including breast cancer screening.

THE RESEARCH

Teaching Cancer Patients to be Self-Advocates, Dr. Merle H. Mishel, Kenan Distinguished Professor of Nursing, University of North Carolina at Chapel Hill

Dr. Mishel stated that there is a gap between cancer treatment and recovery, pointing out that trends indicate the standard patient visit time is down from 15 minutes to 8 minutes, influenced by managed care. There is a need to help patients and caregivers manage treatment side effects and other concerns, yet there is no national system of nursing follow-up care to do this. Certain older minority patients, for example, are apt to leave the hospital without asking questions and without knowing what to do to cope with their conditions. Caregivers, who are often untrained, experience their own health problems, including fatigue, and express uncertainties about their abilities to provide adequate care.

Dr. Mishel and her team tested an intervention that consisted of 15 20 minute telephone calls to patients and their caregivers provided by the same nurse once a week for eight weeks. The study population consisted of 340 rural and urban African American, Hispanic and Caucasian patients with either breast or prostate cancer and 60 caregivers. There were an equal number of controls that received the usual care. The nurses answered questions and provided information about how to be assertive, what questions to ask the doctor, and how to locate free or low-cost resources. Patients and their caregivers received a dictionary of terms to help them phrase their concerns.

The findings indicate that the nurse follow-up approach is highly successful. Patient concerns fatigue, getting questions answered, and ability to take care of themselves were eased by the telephone interventions. They also reported improved problem solving, a greater ability to take care of themselves, fewer treatment side effects, and improved relationships within the family. Caregivers, who reported concerns about their ability to cope and their own health problems, also indicated improvements. For example, caregivers of prostate cancer patients reported that the time they spent helping

patients manage side effects decreased from 3.5 hours to 1.5 hours per week, and their problem solving capability and communication with physicians improved. Comments from study participants, which were 98% positive, included "My only information was from the weekly phone calls," "It was the most helpful thing I ever had," and "The calls were my lifeline."

According to Dr. Mishel, the intervention also reduced phone calls to physicians' offices by 50%, and both patient and caregiver problems were identified early, before they became serious and costly. These follow-up telephone calls by nurses reached underserved and minority populations, and the time they spent handling 16 patients apiece took 5.3 hours weekly compared to the 10 hours reported by many clinicians. She concluded by saying that the intervention can be easily integrated into nursing practice.

Family Caregivers Learning to Care for Loved Ones Living with Cancer, Barbara Given, PhD, RN, FAAN, Professor of Nursing, Associate Director, Institute of Managed Care, Michigan State University

Dr. Given's research examines how cancer treatment affects physical functioning, symptoms, caregiver assistance and utilization of healthcare services. Her study addresses understanding patient problems and how to design interventions delivered by advanced practice nurses that would effectively involve family caregivers in caring for their ill relatives. She discussed findings from a study population of 900 newly diagnosed breast, colon, prostate or lung cancer patients at least 65 years of age and their caregivers, many of whom had not received care information from a health institution. The cohort was followed for a year after diagnosis.

The average time patients spent with a health care professional over a year's time, including while they were receiving such treatment as radiation and chemotherapy, was only seven and a half days per year. They reported pain (62%), nausea, sleep disturbances, diarrhea, poor appetite, fatigue (81%), and depression (30%) for many months. About 82% needed assistance from their families. Only 16% of the patients were referred to home health care.

Dr. Given pointed out that family caregivers are a hidden healthcare resource -- they are not socially or politically visible. The family caregivers in her study were involved in management of the patients' symptoms, mobility, dressings and catheters. They provided at least eight hours of care a week. During the time when patients were receiving treatment for their cancer, 40% of the caregivers reported more than 10 hours a week. Based on 1999 projections of those diagnosed with breast, colon, prostate and lung cancer, this would amount to 345 million uncompensated hours of care, or 165,865 person years.

Employed family caregivers reported missing work (27%), were interrupted at work (27%), missed work without pay (20%), used paid vacation days (27%+), or quit or retired early (12%) to provide care. Caregivers reported that they were left to trial and error in learning the tasks of caregiving. During the first year following the patients' diagnoses of cancer, the family caregivers often use more primary care than their ill relatives do. They were also concerned that the care they provided to their family members with cancer was not sufficient.

Currently, Dr. Given is conducting a randomized clinical study to test an intervention delivered by advanced practice nurses to assist caregivers and patients living with cancer. An earlier pilot study indicated that APNs made a difference in lowering caregiver distress and raising their capabilities to provide sufficient care.

CHALLENGES

The National Cancer Institute estimates that approximately 8.2 million people living today have had, or currently have, cancer. The risk increases with age -- the "lifetime risk" for American men is one in two; for women the risk is one in three. In 1999, approximately 1,222,000 additional people and their families will face the challenges of living with cancer, including the array of treatment choices and strategies to deal with the financial, physical and emotional burdens that often accompany the disease.

The demand for family caregivers, also known as informal caregivers, is increasing. Currently one in four Americans provides some type of care for persons with chronic conditions. Most caregivers are middle-aged women, and many are part of the "sandwich generation" that cares for children and older people simultaneously. At the same time, the supply of these informal caregivers is diminishing, caused by decreasing birth rates and smaller families that consist of more older than younger members.

Informal caregivers are undergirding the healthcare system. Estimates indicate that if they were paid an hourly wage in between the minimum wage and the national rate for home health aides, the nation's healthcare costs would increase by \$196 billion yearly one-fifth of the nation's healthcare costs. Yet many of these caregivers have little information and no training to accomplish multiple tasks that require essential skills. Development and testing of interventions to assist family caregivers in caring for ill relatives and maintaining their own health is a critical area of research.

- Scientific evidence is needed regarding the quality of family care and its effect on patient outcomes
- Strategies need to be devised to identify family caregivers needing assistance and for how long
- Interventions tailored to family needs must be developed in order to provide the knowledge and skills for care and that will promote positive patient outcomes
- In order to fill the gap between cancer patient treatment and recovery, there needs to be a national system of nursing follow-up care to help patients and caregivers with their unanswered concerns.
- Research on nurse follow-up projects should be conducted across different chronic illnesses
- Research should also identify interventions for patients with advanced disease, where symptom control and quality of life are prime concerns
- Cost savings to the healthcare system should be identified that result from satisfactory family home care of patients
- Cost effectiveness of the use of advanced practice nurses should be verified