

Symptom Management for Chronic Neurological Conditions

May 6, 1998

Congressional Breakfast Briefing

The FRIENDS of the NINR held the second in a series of three breakfast briefings this year on *Symptom Management for Chronic Neurological Conditions*. 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 legislators, Congressional staff, nurse researchers and administrators, and members of public and private organizations having a special interest in the topic.

Congressman Lloyd Doggett (D-TX), who sponsored the breakfast, provided welcoming remarks. He was followed by Colleen Conway-Welch, PhD, RN, FAAN, President of FRIENDS and Dean of Vanderbilt University School of Nursing, who introduced attendees and thanked the Eli Lilly Center for Women's Health for hosting the event.

Patricia A. Grady, PhD, RN, FAAN, Director of the National Institute of Nursing Research (NINR), provided the opening remarks. She stressed that managing symptoms of chronic neurological conditions continues to be an important research area of opportunity for nurse researchers and is key to making nursing practice the best that it can be. One of NINR's goals is to facilitate research and to promote excellence in the knowledge base for clinical practice.

Dr. Grady pointed out that as the population ages, people are living long enough to develop the neurological problems of middle and older age, including such neurodegenerative disorders as multiple sclerosis and Alzheimer's disease. These and other disorders, such as childhood epilepsy, have substantial debilitating effects that result in lost quality of life. Strategies for addressing chronic neurological disorders include maintaining improved physical functioning and managing problems such as those related to diet, mobility, sleep, and pain. Current NINR neuroscience research is characterized by support in four major areas:

- Managing cognitive impairment in Alzheimer's disease
- Assessing and managing acute and chronic pain
- Understanding sleep and managing sleep disorders
- Caring for patients with such conditions as multiple sclerosis, epilepsy, Parkinson's disease, spinal cord injury, and stroke.
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Dr. Grady concluded by saying that neuroscience nurses are at the forefront of some of the most exciting avenues for scientific discovery to enhance the understanding and management of chronic illness.

The Research:

Study of Health Promotion Behaviors of People with Multiple Sclerosis

Alexa Stuijbergen, PhD, RN, FAAN

Associate Professor, School of Nursing
University of Texas at Austin

Dr. Stuijbergen stated that 75 percent of disabilities are caused by chronic illnesses, such as multiple sclerosis (MS), cancer, stroke and arthritis. MS is a disease that mainly affects Caucasians and strikes during the middle years of life (20-40 years of age), a period of significant family and career obligations. The disease is a demyelinating disorder of the central nervous system in which the body's immune system attacks its own tissues. The result is a destruction of myelin, the fatty casing that insulates nerve cell fibers in the brain and spinal cord. Damaged myelin may slow or block communication between the brain and other parts of the body.

It is estimated that 350,000 people have MS, with symptoms varying from mild to debilitating. About 73 percent are women, who experience greater disability and often have lower incomes than men. MS does not significantly alter the lifespan -- people may live a long time with the disease. Although the severity of symptoms vary, the disease progressively worsens. MS costs the nation \$20,000 per person per year; costs of new drug treatments that slow the progression of MS are an additional \$11,000 per year.

Dr. Stuijbergen has been actively involved in research of health promotion strategies that can blunt the negative effects of MS and improve the quality of life. More than 800 people with MS are participating in her projects. So far, the studies have documented a high interest in health promotion and self-care among those in the patient population. The response rate averages are greater than 88 percent. Many patients indicate that health promotion activities, such as exercise, nutrition, and stress management, have enabled them to continue to live independently in the community and maintain what has been called the "narrow margin of health." Her studies have also demonstrated the critical role of nursing in promoting healthy behaviors, reducing illness-related impairments, such as loss of mobility, and decreasing the fatigue experienced by many MS patients.

Dr. Stuijbergen continues to analyze such issues as the proper exercise for MS patients who do not tolerate heat well, and optimum techniques to promote good nutrition and mobility. She is also following patients over time to assess the durability of changes of behavior and their effects on the disease.

Understanding the Experience of Children with Epilepsy: Going Beyond Medical Treatment:

Joan Austin, DNSc, RN, FAAN

Professor, School of Nursing
Indiana University

In describing issues associated with epilepsy, Dr. Austin indicated that the disorder affects about one percent of children nationwide and is among the most prevalent childhood chronic conditions. Most children not only suffer from repeated seizures, but also experience a series of mental health and academic achievement problems that can negatively impact their quality of life through adulthood. People with epilepsy during childhood are four times more likely to be unemployed or underemployed as adults. The associated cost of epilepsy to society is significant -- federal government estimates indicate \$3.5 billion annually.

Research on children with epilepsy traditionally has focused on biomedical factors, such as causes of seizures and medical treatments. Dr. Austin indicated, however, that controlling seizures is not the complete answer, because over half of the patients have mental health problems, and two-thirds have academic problems, even the great majority of them who have normal intelligence. Her research focuses on these areas in order to improve quality of life.

Epilepsy poses serious challenges for children. These young people, particularly girls, often have a poor self-concept and a high level of anxiety caused, among other things, by the stigma attached to the disease. Moreover, children continue to have serious quality of life problems even after their seizures have stopped. Another issue is that poor academic achievement in boys may not be reversed once epilepsy is outgrown. Nonetheless, there is evidence of protective factors, since some children do well. Dr. Austin's research is aimed at discovering these protective factors and whether they can be replicated in children who lack them.

Currently, Dr. Austin is identifying the effects of, gender, neurological factors, including seizures, family issues, and perceptions on young people with epilepsy. She is also investigating how quality of life problems interface with biological problems. Her research is setting the stage for development and testing of individually tailored interventions for these patients and their families.

CHALLENGES

Chronic neurological conditions affect people of all ages, from infants with congenital brain malformations to elderly individuals living with Alzheimer's disease. These conditions lead to symptoms such as decreased neurologic and motor function, dementia, chronic pain and seizures. People affected by illnesses such as AIDS and a variety of cancers can also face chronic neurological complications resulting from their conditions or treatments that negatively impact their quality of life. The cost of these conditions exacts an enormous toll on the nation's health care resources. To provide one example, the American Heart Association indicates that the total direct and indirect cost in 1996 of stroke alone was \$43.3 billion.

Multiple Sclerosis

- For patients with MS, who must live with the disorder for the rest of their lives, research is needed to help them maintain their independence and lifestyle for as long as possible. These patients face uncertainty of the disease course and must cope with its effects, while attempting to fulfill their family and work obligations and live normal lives.

- More needs to be known about health promotion interventions that are both effective and acceptable to MS patients. The influences of exercise, nutrition, stress reduction, self-esteem, and family and other support networks on MS are important areas for research.

Childhood Epilepsy

- Behavioral research is needed that addresses mental health problems of children with epilepsy, including studies that identify protective factors for successful adjustment; identify biological and behavioral risk factors; and develop and test programs tailored to the individual needs of the child and the family, including handling stigma and seizure management and improving quality of life.
- Academic achievement problems need to be addressed, including studies that describe patterns of achievement over the course of the condition; identify risk and protective factors for academic underachievement; develop and test programs tailored to the child's specific neuropsychological and learning strengths and weaknesses; and develop programs for school personnel to reduce academic underachievement in children with epilepsy.
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Presenters:

Alexa Stuijbergen, PhD, RN, FAAN
Associate Professor, School of Nursing
University of Texas at Austin

Dr. Alexa Stuijbergen, has been actively involved in research and clinical practice with persons experiencing chronic conditions for over 20 years. Her work focuses on exploring ways that persons maximize their health and quality of life in the context of living with chronic and disabling conditions. Most recently, she has addressed the issues of health promotion and quality of life for persons with the chronic neurological condition of multiple sclerosis. Dr. Stuijbergen is an Associate Professor at the University of Texas at Austin School of Nursing and a Fellow of the American Academy of Nursing. She has published widely and serves in leadership positions for the Association of Rehabilitation Nurses and the National Multiple Sclerosis Society. She is presently a member of the Department of Health and Human Services subcommittee formulating health promotion objectives for persons with disabilities for inclusion in Healthy People 2010.

Joan K. Austin, DNS, RN, FAAN
Professor of Nursing
Indiana University School of Nursing

Dr. Austin has conducted research on adaptation to childhood epilepsy for 18 years and has over 100 publications. Her research, which focuses on quality of life problems in youth with epilepsy, has been funded by the National Institute of Nursing research, the National Institute of Neurological Disorders and Stroke, and the U.S. Department of Education. In 1993 she was the first nurse scientist to receive the American Epilepsy Society/Milken Family Foundation Research Award. Her research also has been recognized by the Midwest Nursing Research Society, the American Nurses Association's Council of Psychiatric and Mental Health Nursing, and Sigma Theta Tau International. In 1995 she received a Special Recognition Award from the Epilepsy Foundation of America for her research and service to the organization on its Professional Advisory Board. Dr. Austin was a member of the Expert Panel on Epilepsy Rehabilitation Research for the National Institute on Disability and Rehabilitative Research at the U.S. Department of Education. She also served on two panels that made recommendations to the Centers for Disease Control and Prevention regarding research priorities for enhancing quality of life of persons with epilepsy.