Summary of the Capitol Hill Breakfast Briefing on

Quality of Life for Transplantation Patients

May 18, 1999

The FRIENDS of the National Institute of Nursing Research held its second of this year's three Congressional breakfast briefings on May 18, 1999. The topic was Quality of Life for Transplantation Patients. FRIENDS, an independent, non-profit 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 briefings included 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, President of FRIENDS and head of the Division of Nursing, New York University, provided brief welcoming remarks and thanked Congressional sponsors of the event Senator William Frist (R-TN), and Representatives Louise Slaughter (D-NY) and Nancy Pelosi (D-CA). She also thanked the corporate sponsor, Baxter International.

Patricia A. Grady, PhD, RN, FAAN, Director of the NINR, provided introductory remarks, stating that the quality of life for transplantation patients, one of NINR's areas of research opportunity, is a serious public health concern. Each year, more than 12,000 Americans undergo organ transplants. And people are living on complex therapeutic regimens for more than 20 years after receiving transplants. As a result, the issue of quality of life is emerging as an important one for patients and nurse researchers.

Before introducing the speakers, Dr. Grady announced the opening of the Solid Organ and Tissue Transplantation Unit at the NIH Clinical Center.

THE RESEARCH

Quality of Life in Patients with End-Stage Renal Disease: The Effects of Physical Activity, Patricia Painter, PhD, FACSM, University of California at San Francisco, School of Nursing

Dr. Painter, an exercise physiologist, stressed that physical functioning is "a keystone for quality of life." She discussed her multidisciplinary program of research to improve, through exercise, the health of renal failure patients who are on dialysis or who have had kidney transplants. Every day more than 100 people are diagnosed with end-stage renal disease. Although no respecter of race or socioeconomic status, end-stage renal disease has a tremendous impact on older adults and on ethnic minorities. It is imperative that these people be helped through scientifically tested strategies to improve their quality of life during dialysis or after surgical transplantation.

Dialysis patients typically live with extreme physical impairment, and self-reported poor physical functioning is a major predictor of adverse outcomes, such as hospitalization and mortality. Fewer than 10% of these patients participate in regular physical activity. Patients who have had successful transplants initially show improved physical functioning, but unless they adopt a program of regular physical activity, over time they will become as impaired as patients on dialysis.

Physical inactivity is a risk factor for cardiovascular disease (CVD), and CVD is the major cause of death in endstage renal disease patients. Hypertension occurs in 6090% of dialysis patients and 4070% in post transplant patients. Muscle strength and joint function are also compromised. Excessive weight gain is common in transplant patients 45% are considered obese.

Dr. Painter's research evaluates the effects of physical activity interventions on dialysis and transplant patients' cardiovascular risk profiles, physical functioning, and quality of life. She is finding that regular physical activity is important to health-related quality of life and has potential in reducing CVD risk factors in both dialysis and transplant patients. Since physical activity is a "lowtech" intervention, it may be cost effective in reducing the costs of institutional care for elderly dialysis patients, as well as other costs associated with rehospitalizations and caregiving for both dialysis and transplant patients.

Enhancing Quality of Life for Transplant Recipients, Donna K. Hathaway, PhD, RN, FAAN, University of Tennessee, Memphis, School of Nursing

Dr. Hathaway began her talk by providing some facts about kidney transplantation. About 90,000 Americans are currently living with a transplanted kidney. Waiting lists for kidneys continue to expand, but unfortunately, organ donations do not. The median waiting time is nearly three years. Sixty percent wait at least a year, and each year over 2,000 people die while waiting.

Transplantation is very successful at extending life - and between 88 and 94% of the transplants are functional. The 5-year survival rate is 81% compared to 37% for dialysis patients; 72% versus 28% respectively for people who also have diabetes. Overall quality of life is improved significantly and is sustainable over time. Transplantation is also cost effective. Medicare payments for a year of post-transplant care averages $17,599 versus $55,357 for dialysis.

Dr. Hathaway then described some of the challenges faced by transplant patients. They must make adjustments not to illness, but to new health. Yet they must guard against the chronic health problems commonly associated with aging, such as CVD, high blood pressure, and cancer, which are accelerated in these patients. Healthy lifestyles, such as proper diet and exercise, take on new importance. And integrating complex medication regimens into daily life, including managing adverse effects, is a critical component of a transplant patient's life.

In discussing her research, Dr. Hathaway is testing a 3 pronged model of care for post-transplant patients that focuses on decreasing adverse events, facilitating employment, and enhancing social support. Making patients partners in their care is another important element of her study, and they are taught how to perform their own health assessments in order to detect adverse events early when treatment is more successful. An employment counselor is available to help patients go back to work, and social support is addressed through group and individual interventions. Together these three aspects of care potentially can improve quality of life for transplant recipients, reduce health care costs, strengthen family relationships, and make productive lives possible.

Dr. Hathaway's program of research uses a multidisciplinary team that includes nursing, pharmacy, medicine, social work, exercise physiology, biostatistics, health economics, and basic sciences. Both staff and patients are willingly adopting the healthcare model. Patients are assuming a greater role in their care and do so capably and enthusiastically.

CHALLENGES

Transplantation patients used to be hospitalized a week to 10 days following surgery. With shortened hospital stays, they now stay about 4 days. This increases the stakes for health care professionals and patients to form a successful partnership for good health and quality of life. The professional's time is compressed to help the patient with the transition to home and normal life, and to ensure that the patient understands physical assessment and self-care. Continual contact with the patient by phone or other means is important. The patient, too, must participate fully in the partnership by being alert to body signals of trouble and by willingness to make lifestyle changes, if necessary, and pay heed to diet, exercise and medications. Furthermore:

• Counseling and programs of physical activity are not standard as part of medical recommendations for either dialysis or transplant patients. Strategies are needed to bring this about.

• Along with the improvement of the medical technologies associated with dialysis and transplantion, there is a need for more research on the benefits of health promotion in reducing long-term complications and promoting quality of life.

• Factors should be identified that promote long-term adherence to medical and behavioral regimens.

• Protocols need to be developed to reduce life-threatening side effects of medications.

• Differences in quality of life outcomes among patients point to a need to identify the responsible factors and to design approaches to maximize quality of life for all transplant patients.

• Since family members assume responsibilities for patient care, studies on caregiver health and well being are needed.

• Longitudinal studies are needed to assess graft function, health and quality of life, particularly since the life span of transplants continues to increase.

• Studies of issues related to future therapies, such as xenotransplantion and biologicallydesigned body parts, should be designed in anticipation of possible changes in health care practice.