

DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH

Fiscal Year 2002 Budget Request

Witness appearing before the
Senate Subcommittee on Labor-HHS-Education Appropriations
May 23, 2001
and
House Subcommittee on Labor-HHS-Education Appropriations
May 16, 2001

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National Institute of Nursing Research

May 23, 2001

Mr. Chairman and Members of the Committee:

I am pleased to present the President's budget request for the National Institute of Nursing Research (NINR) for FY 2002, a sum of \$117,686,000, which reflects an increase of \$12,508,000 over the comparable Fiscal Year 2001 appropriation.

This year, as NINR celebrates its 15th anniversary, it is encouraging to reflect on the progress made so far. Nursing research on a broad range of issues has been stimulated, developed, funded, published, and integrated into practice, where patients and the public are already reaping the benefits of improved health care. Studies include improving management of symptoms and quality of life for the increasing population of patients with longstanding chronic illnesses; smoothing the transition of advanced technologies into people's lives, such as genetic screening and telehealth; reducing health disparities among minorities and those without adequate access to the healthcare system; and improving care at the end of life. Yet nursing research is a young science. It must continue to grow to help meet urgent national health needs, expectations of our nation's people, and requirements of 2.7 million registered nurses for well-tested, effective interventions. NINR research is central in supplying empirical evidence that expands the scientific base for care affecting people's physical, psychosocial, and cultural needs.

TRANSLATING RESEARCH FINDINGS INTO PRACTICE AT THE COMMUNITY LEVEL

Let me illustrate how nursing research can influence public and private organizations at the community level – and in so doing, help eliminate health disparities. NINR study findings addressed an important health issue -- low birthweight and preterm births -- and supported research that promoted lower incidence while decreasing costs to the healthcare system. According to the National Center for Health Statistics, the United States is a disappointing 26th among industrialized nations in the number of babies per 1000 dying before their first birthday. The national rate is over 7 deaths per thousand. For African-Americans it is over 14 per thousand. In North Carolina, where the study took place, investigators targeted low-income African American pregnant women and Caucasian women at particular risk for low birthweight, including pregnant teens. This five-year project involved a home visit followed by low-cost, low-tech phone calls by registered nurses to monitor health and address problems of the women. Results showed that the low birthweight rate for the treatment group was 10.9 percent, compared with 14 percent for controls. For African Americans 19 years and older, the results were even more pronounced – 11 percent in the treatment group versus 17 percent for controls. For this group, cost savings to the hospital

were \$277 per pregnancy. Extended savings also resulted from a reduction in long-term problems related to low-birthweight.

Investigators expanded the intervention to four programs that included Hispanics, African-Americans and Caucasians -- three programs focusing on low-income women and one on women of all income levels nationwide. The results equaled or bettered the original study findings. All four programs are continuing today without Federal research funding -- having been adopted by private sector organizations, including a national HMO.

IMPROVING DAILY LIVING FOR ALZHEIMER'S DISEASE PATIENTS

This anniversary year presents the opportunity to recognize some notable nursing science advances. For example, with respect to Alzheimer's disease patients, an important goal is preserving their functional capacity as long as possible so that they can bathe, dress and feed themselves. Researchers studied nursing home residents with Alzheimer's disease – the most disabled group in these establishments. Their disabilities were found to be caused by cognitive deficits, but also by the staff's inability to encourage independence. This can cause disability beyond what can be expected of cognitive impairment alone. The study involved nursing home staff instituting one-to-one interventions to improve the residents' abilities to bathe and dress. First, the residents were examined to determine which skills they retained. Then the physical and social environment was restructured to reactivate those skills. Findings indicate that the intervention improved residents' bathing and particularly dressing capabilities, and disruptive behaviors were reduced. Improvements were realized within five days' time and were maintained by the end of three weeks. To achieve this, however, staff time with each resident increased. Investigators hypothesize that the amount of time can be reduced if the goal is to maintain the residents' skill levels, rather than to raise them.

END-OF-LIFE/PALLIATIVE CARE RESEARCH

Another issue predominantly affecting seniors, but also affecting people of all ages, is how to retain quality of living during life's final phase. NINR has a special interest in this area and is the Institute that coordinates end-of-life research at the NIH. A major issue is that, while capable of enhancing life, technologies and treatments can also involve burdensome procedures that may be futile and prolong discomfort and pain. The decision whether or not to withdraw life support, usually made by family members or friends on behalf of the dying patient, is a difficult decision to make. NINR researchers measured family member stress levels and found them to be twice as high as those due to other

serious crises, such as construction disasters, or losing a home to fire. This study is one of the first to show that existence of an advance directive eases stress on the family when life-sustaining treatment is withdrawn. When an advance directive existed to guide decisions, the families were better able to focus on patients' quality of life and less likely to choose prolonging life at all costs.

FACTORS INFLUENCING OBESITY IN ADOLESCENTS

Obesity can decrease quality of life and shorten life span. According to the Centers for Disease Control and Prevention, 13 percent of children and 14 percent of adolescents are overweight, continuing the pattern of the past two decades. These young people are at risk for cardiovascular disease later in life. In a study of 2000 adolescents, a nurse investigator found that for both males and females, the influence on obesity of ethnicity and socioeconomic status was greater than the influence of watching TV or playing video games. African-American teens and low-income female teens were at special risk, which suggests where the emphases of prevention programs should be placed. The study also indicated that participation in high-intensity exercises, such as basketball or swimming, may protect boys against obesity. School physical education and community recreation programs that feature high-intensity physical activities could help lower the obesity rate. Further research is needed, however, before programs can be developed for girls.

NEW AND EXPANDED INITIATIVES

Turning to the immediate future, next year NINR plans an increased emphasis on chronic illness. The rise in chronic illness creates an escalating demand for strategies that enable people to live as normal lives as possible, even while they are dealing with chronic illness. Another key factor is caregiving for family members at home. This practice is increasing in importance as an essential ingredient of the Nation's healthcare system.

The chronic disease of cancer has special urgency for minorities, because it is they who bear an unequal burden for this disease. The Healthy People 2010 report states that African Americans are 34 percent more likely to die of cancer than are Caucasians. New ways must be found to reverse this disturbing trend. NINR plans to concentrate on culturally-sensitive prevention research that focuses on lifestyle factors, such as alcohol, poor diet, and exposure to environmental toxins. We will also develop and test innovative approaches to increase screening for cancers in minorities, which should help reduce disease or bring balance to the present unevenness of disease expression among populations.

Chronic pain, prevalent throughout our society, is frequently the reason people visit doctors and hospitals, and it can significantly influence recovery from illness. Imagine, however, being in severe pain but not able to tell the nurse or doctor about it. Many people are in this position, which makes pain treatment all the more difficult. Examples include those who may be cognitively impaired, or cannot speak English, or are infants unable to talk yet. Next year NINR plans a new emphasis on pain. Researchers must discover cues that indicate the presence and degree of pain so that adequate treatment can be provided for those who cannot speak for themselves. Research is also needed to address other barriers to the effective treatment of chronic pain, including under-reporting of pain and underutilization of analgesics.

Frequently accompanying chronic illness is cachexia, a condition signaled by muscle wasting and weight loss. Patients with cancer, cystic fibrosis, AIDS, and chronic lung disease are at risk for cachexia. The impact on quality of life stems from fatigue, weakness and susceptibility to other complications. Despite promising opportunities, there has been limited research attention to this condition. The urgent needs of patients with long-standing illnesses dictate that cachexia must be addressed.

Those who care for ill family members are sometimes overlooked in the overall battle against chronic illness. Yet according to the Center for Advancement of Health, nearly one in four families in our country are involved not only with physical care of their relatives, but also in dealing with behavioral or cognitive problems. Yet many caregivers must still shoulder their other responsibilities of daily life. The combination of these demands can put them at risk for poor health, caused in part by the stress of caregiving and perhaps their own advanced years. NINR plans to increase research in this area, including studies to promote learning and refining caregiving skills to benefit the patient, and strategies to safeguard caregivers' own health and quality of life.

BUILDING THE CAPACITY TO DO NURSING RESEARCH

NINR must also ensure that the nation maintains a sufficient, well-prepared supply of nurse researchers to provide the empirical evidence necessary for clinical nursing practice. NINR offers a variety of NIH training opportunities, including those emphasizing patient-oriented research and research conducted by and involving minorities. We must also address the concerns of the recent report of the National Research Council on the needs for biomedical and behavioral scientists. The report recommended that NINR emphasize research training that facilitates earlier entry into research careers. To address this concern, NINR has designed

several innovative programs to attract students to early research careers and to shorten the entry time into research. We also plan to continue our successful Summer Genetics Institute to fill the need for expert nurses prepared to address the many issues raised by genetic advances.

In closing, contemporary and future biomedical and behavioral research will continue to emphasize many aspects of what nurses do well – such as ethnic and culturally sensitive approaches, health promotion, and symptom management – all strong research emphases of NINR. NINR must continue to build good science in these critical areas.

The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report which compared our FY 2000 results to the goals in our FY 2000 performance plan. As performance trends on research outcomes emerge, the GPRA data will help NIH to identify strategies and objectives to continuously improve its programs.

I would be pleased to answer any questions the Committee may have.

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