

# News from NINR

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## A Successful Kickoff

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On October 11, 2005, the National Institute of Nursing Research (NINR) held a very special symposium—"Nursing Research: Changing Practice, Changing Lives"—to kick-off our year-long 20th Anniversary celebration. This symposium served to highlight many of the accomplishments of NINR and its scientists in advancing nursing science, and to showcase the positive impact that our work has had on the lives of millions of Americans.

The National Institute of Nursing Research first opened its doors in 1986, as the National Center for Nursing Research (NCNR), with much hope and anticipation that nursing research would make important contributions to the science of health care. At the symposium, we honored 3 outstanding individuals: Dr. Doris Merritt, the first acting Director of the NCNR, Dr. Ada Sue Hinshaw, the first permanent Director of the NCNR/NINR, and Dr. Suzanne Hurd, acting Director of NINR. I am proud to follow in their footsteps as the current Director of NINR. These distinguished leaders were instrumental in building the nursing research enterprise in its early years at the National Institutes of Health (NIH), and their dedication, energy, creativity, and diligence have contributed to the success of NINR. It was due to their efforts that the new Center/Institute was able to meet the challenges of becoming part of the NIH, educating Congress about nursing research and creating opportunities for building nursing science within the federal environment.

This symposium affirmed the aspirations of the early pioneers of nursing research who understood the importance of having a national focal point in the federal government to showcase and provide support for their work in order to cultivate a science that was then in its early stages. In the ensuing years, research supported by NINR has reduced the impact of illness, lowered health care costs, and resulted in improved health and quality of life for individuals in all stages of life.

## SYMPOSIUM PANELS

The symposium opened with panel sessions and a discussion on end-of-life care. Since our designation in the late 1990s as lead institute at NIH for end-of-life research, NINR has helped to frame the fundamental issues related to this relatively young area of research. Dr. Pamela Hinds of St. Jude's Children's Hospital presented research showing that how we facilitate end-of-life decisions for families may influence quality of survivorship for all involved. She has found that many adolescents with terminal cancer

understand and want to be included in care decisions, and parents want caregivers to be honest with them and to help their child avoid suffering. Dr. William Breitbart of the Memorial Sloan Kettering Cancer Center argued that we need to expand the definition of palliative care to include psychiatric, psychosocial, existential, and spiritual domains of care. His research has indicated that a strong sense of spirituality helps to decrease depression and hopelessness in terminal cancer patients. Dr. Kathleen Puntillo of the University of California, San Francisco, presented her findings on dying patients in the intensive care unit (ICU). She has shown that many of these patients are able to participate in symptom assessments, that they experience many distressing symptoms such as pain, anxiety, and thirst, and that caregivers and family members often underestimate the burden of these symptoms.

The second session was devoted to the impact of HIV/AIDS and health disparities, another important part of the NINR research portfolio and a major social and healthcare problem worldwide. Dr. Antonia Villarruel of the University of Michigan started her talk by acknowledging that 20 years ago she was a part-time doctoral student, and that funding from the NCNR helped support her training and launch her research career. She presented her current findings on an HIV prevention program for Mexican youths and Latino youths living in the US; a program that succeeded in reducing sexual activity and improving knowledge about HIV prevention. Dr. Margarete Sandelowski of the University of North Carolina at Chapel Hill discussed the use of qualitative research methods and new analytic and interpretive techniques in research on women with HIV/AIDS. The long-term goal is to enhance the use of qualitative findings as a basis for both research and practice. Dr. Loretta Jemmott of the University of Pennsylvania pointed out that researchers have to partner with the community to better design, evaluate, and implement culturally appropriate interventions. From her research, she has developed programs for minority women, adolescents, and families that reduced HIV risk behaviors, promoted abstinence among those who were not sexually active, and decreased the incidence of sexually transmitted diseases. She also related how some of her work is being widely tested for implementation by the Centers for Disease Control.

During the third session, we heard how new and emerging technologies are being used and adapted to improve the health of individuals. Dr. Judy Matthews

from the University of Pittsburgh described the “Nursebot” project, an interdisciplinary venture of the University of Pittsburgh, Carnegie Mellon University, the University of Michigan, and Stanford University. As an adjunct to home health nursing, the nursebot is a mobile, programmable robot that can be used with home-bound elders and others with chronic conditions to help them to ambulate and to remind them to take medications. This project, which draws on the talents of researchers with backgrounds in psychology, occupational therapy, design, mechanical and electrical engineering, computer science, robotics, and nursing, is a great example of the interdisciplinary teamwork often needed to advance science. Dr. Ann Cashion of the University of Tennessee Health Science Center and a graduate of NINR’s Summer Genetics Institute spoke on incorporating emerging genetic methods in the care of transplant patients. Rejection is a major problem with pancreas transplant recipients, and her research group is testing whether genetic expression of biomarkers may predict the early stages of rejection. These studies illustrate how genetic research applies to patient care, and how nurses can use genetic methods to assess patients and affect outcomes. Dr. David Gustafson of the University of Wisconsin at Madison reported on the Comprehensive Health Enhancement Support System (CHESS) study, using the Internet to help individuals with chronic conditions learn how to improve their symptom self-management and their quality of life. The CHESS Web site provides high quality information on a range of chronic conditions and allows persons to discuss their symptoms and health problems with others, as well as to seek information and advice from health care providers. One very popular section of the Web site is devoted to pages for children. Studies of the effectiveness of the CHESS program are ongoing.

Symptom management and health promotion, central to nursing practice, have been core research areas at NINR from the beginning. In the final session, we heard about novel methods to manage the impact of symptoms in a range of patient populations. Dr. Ki Moore of the University of Arizona discussed her program to decrease the learning deficits that can impact children hospitalized for acute lymphoblastic leukemia (ALL), a once fatal but now largely treatable cancer. Chemotherapy for ALL can have many subtle cognitive effects on the developing brain of a child. Dr. Moore and her team have implemented a math tutorial intervention for these children that helped to prevent or reverse their declines in school performance. Dr. Alexa Stuijbergen of the University of Texas at Austin, and one of the first to receive a pre-doctoral F31

research training grant from the NCNR, discussed the impact of health promotion behaviors on chronic disease. Her research has demonstrated that exercise can help slow the functional decline often seen in persons with multiple sclerosis (MS), a variable and often unpredictable disease. This research brings into focus “the strengths and positive resources that people use in their everyday lives” to enhance their quality of life. Finally, Dr. Jean McSweeney of the University of Arkansas for Medical Sciences described her findings of gender differences in the symptoms of heart disease. Her most recent research findings indicate that Black women experience certain early symptoms of heart disease, such as fatigue and discomfort, differently than White women. This information provides an important clue to help address the persistent health disparities in care and outcomes for minority populations.

Elias Zerhouni, MD, Director of NIH, also attended the Symposium. Dr. Zerhouni spoke to the audience and congratulated NINR on its accomplishments over the past 20 years. He highlighted the impact nursing research has had within NIH and the health care sciences.

## LOOKING TO THE FUTURE

In the year 2000, as we entered the new millennium, we had occasion to contemplate the future with a sense of infinite possibilities. While we were aware that our science was still developing, we knew we had already made significant contributions to healthcare practice and patient-oriented research.

Now, a brief 5 years later, we continue the process with excitement and expectations for success. The symposium planned for next October, concluding our year-long Anniversary celebration, will explore the future of nursing research. How can we capitalize on interdisciplinary research? How can we best transform and integrate nursing research priorities into the priorities of NIH and the needs of the public? And most important, how can we effectively transfer our research results into healthcare practice to benefit patients?

Nursing research, by design and by necessity, covers a broad spectrum. We are fortunate to have such an abundance of opportunities for creativity, dedication, productivity, and achievement. I am honored and inspired to be a part of this enterprise. Thanks to the vitality and resiliency of nurse researchers, I am confident that our science will continue to deepen and expand as we work to make a significant difference to the health care and quality of life of people throughout the US.