ON OCTOBER 19, 2005, researchers from the University of Pittsburgh School of Nursing met at the Oncology Nursing Society to present an overview of several areas of research at the School. A single day was not enough time to cover all current research at the School, but representatives from six areas highlighted recent studies in oncology, genetics, acute and critical care, adherence, technology, and informatics. Presentations featured the overarching research themes in each area, using language common for all audiences, including the media, academic, scientific, and lay populations.

Future issues of Pitt Nurse will highlight other areas of research at the School, including:
• Adolescent health, with a focus on pregnancy, smoking, stress, suicide, and at-risk behavior;
• Chronic disorders, with a focus on AIDS, cardiovascular and cerebrovascular diseases, diabetes, obesity, and liver disease;
• Healthcare outcomes, with a focus on length of stay, cost, job satisfaction, nurse-patient outcomes, and medication errors;
• Women’s health, with a focus on infertility, postpartum depression, pregnancy and its complications, and menopause; and
• Qualitative and quantitative research.

Researchers at the School do not operate in “silos” of expertise. The presenters demonstrated many overlaps and commonalities, as well as intradisciplinary and interdisciplinary connections among all areas of nursing research. In addition, the presentations outlined a growing network of multidisciplinary collaborations with other schools at the University of Pittsburgh as well as with groups and schools outside the University.

OVERVIEWS OF THE PRESENTATIONS are highlighted on the following pages. A summary list of all currently funded research at the School is on pages 26–27 of this issue, and a list of research collaborators and a list of current funding sources are on page 28. More information about individual studies is available on the research link of our Web site, www.nursing.pitt.edu.

FACILITIES AVAILABLE to researchers within the School include:
• The Center for Research & Evaluation;
• The Center for Chronic Disorders, a center funded by the National Institute of Nursing Research (NINR) and headed by Dean Jacqueline Dunbar-Jacob, PhD, RN, FAAN;
• The Molecular Genetics Laboratory;
• And the newly established Clinical Research Suite, which is used to conduct clinical research, consultation sessions, and focus group sessions.

“OUR ABILITY to excel in a wide range of research makes us a leader in nursing research,” says Janice S. Dorman, PhD, MS, associate dean for scientific and international affairs and professor in the Department of Health Promotion and Development. “We are on the cutting edge of using research to influence practice.”

With the NINR gearing up for its 20th-anniversary celebration in 2006, the institute is focusing on nursing research that impacts people’s lives and patient care. The School is on target with this objective.
The first graduate oncology nursing specialist program in the country was established at the University of Pittsburgh School of Nursing in 1968. In 1973, the National Cancer Institute awarded the School a contract to expand the oncology component of the medical surgical master’s program and develop continuing education programs in oncology nursing.

Additionally, prominent nurse researchers at the School have conducted oncology research that has significantly impacted treatment for cancer patients. A multidisciplinary oncology nursing research group has come together including faculty representatives from each department. Along with their individual research, group members work on several ongoing collaborative projects, have presented research results nationally, and published together.

Getting life back to normal can be a challenge for women following breast cancer treatment. Catherine M. Bender, PhD, RN, assistant professor in the Department of Health and Community Systems, is working collaboratively with researchers from the University of Pittsburgh School of Nursing.
Pittsburgh School of Medicine, Emory University School of Medicine, and the University of Washington School of Nursing to study cognitive function and mood related to cancer treatment.

Following breast cancer therapy, women report problems with memory, attention, and decision making. These women have been told they are probably cured of their disease—they maintain their jobs, their families, and social obligations—but they say they just can’t multitask the way they used to. And their families may not understand—the families want to move on, but their loved one isn’t the same person she was before her diagnosis.

Bender is not only describing the problem but looking at the potential physiological underpinnings of the problem. With funding from the National Institutes of Health (NIH), Bender is testing behavioral and pharmacological interventions to ameliorate cognitive impairment and prevent depression associated with cancer treatment. Pharmacologic interventions her group has studied include giving patients antidepressants prophylactically before they start treatment. The group also has looked at behavioral interventions such as teaching compensatory strategies to help patients handle the problems they experience as a result of their cancer treatment. The goal of Bender’s studies is to get patients’ lives back to as close to normal as possible following cancer treatment.

Bender also is leading a project funded by Oncology Nursing Society (ONS) tobacco settlement funds. Working with researchers from the ONS and the oncology nursing research group at the School of Nursing, Bender is looking at how symptoms cluster in people with cancer as a comorbidity with other chronic illnesses. A symptom cluster is three or more concurrent symptoms that are related to and influence one another. As the number of cancer survivors increases, it is important to know how a past diagnosis of cancer influences the symptom clusters experienced with other chronic health problems.

**WOMEN DIAGNOSED** with ovarian cancer also must cope with symptoms from the disease and its treatment. Heidi S. Donovan, PhD, RN, assistant professor in the Department of Acute and Tertiary Care, is researching symptom management in women diagnosed with ovarian cancer. In collaboration with the National Ovarian Cancer Coalition, Donovan has conducted research to describe the symptoms these women experience, the cognitive and emotional responses to multiple symptoms, and how symptoms affect coping and quality of life.

Using that information, Donovan developed an innovative psycho-educational intervention to help women with recurrent ovarian cancer manage their multiple symptoms. With funding from the NIH, Donovan and co-investigators from the University of Pittsburgh and the University of Wisconsin are evaluating the feasibility of nurses delivering this intervention via secure Internet message boards. In addition, they will be evaluating whether the Internet-based intervention helps women with recurrent
ovarian cancer reduce the severity of their symptoms and improve their quality of life.

Donovan also is looking at how women with ovarian cancer communicate with their healthcare providers about their many symptoms and side effects. In collaboration with clinicians at Magee-Womens Hospital of UPMC, she is assessing women’s beliefs about symptom management that may interfere with symptom reporting.

**Margaret O. Rosenzweig, PhD, RN**, assistant professor in the Department of Acute and Tertiary Care, believes advanced practice nurses can improve outcomes for patients with metastatic cancer.

With a K07 award from the National Cancer Institute, she is studying the influence of demographic and racial variables on the experience of metastatic breast cancer. Working collaboratively with the Center for Minority Health at the Graduate School of Public Health and the University of Pittsburgh Cancer Institute, Rosenzweig not only looks at treatment decisions, but also at the symptom experience, the severity of those symptoms, and how those symptoms are managed as women receive care for metastatic breast cancer. Preliminary findings indicate that low-income minority women experience greater symptom distress and social distress, and have greater informational needs during metastatic breast cancer treatment than wealthier minority women and all white women.

Rosenzweig also has developed an expansive database with information about women with metastatic breast cancer. Researchers in multiple disciplines have used the database to answer important research questions.

**Paula Sherwood, PhD, RN, CNRN**, assistant professor in the Department of Acute and Tertiary Care, is looking at the hidden costs of care in patients diagnosed with breast, ovarian, colorectal, and brain cancer. Sherwood is collaborating with Bender, Donovan, and Rosenzweig on a pilot study funded by the Center for Research & Evaluation that is designed to understand how the financial stress that can accompany chemotherapy treatment influences severity of symptoms, adherence to treatment regimens, and patients’ overall emotional health.

Sherwood also is interested in the behavioral and biological stresses that can result from providing care for a family member with cancer. In a pilot study funded by the University of Pittsburgh Cancer and Aging Center, Sherwood is studying psycho-behavioral responses, immune function, and overall health in individuals who provide care for a family member with a primary malignant brain tumor.

One caregiver says: “Looking back, I don’t know how I did it. Twenty-four seven—change diapers, take blood, give needles, cook, clean, change him, shave him, medicate him, go to all of his appointments, do endless hours of research, run around town to get his medical stuff, and of course massage him and exercise him, sit with him,”
and above all, shower him with love and affection—that was the easy part.”

Sherwood's goal is to develop and test interventions to help caregivers cope with the stress of caring for a loved one with cancer.

**Uncertainty is the greatest source of psychosocial distress for children diagnosed with cancer.** Patients and their families are faced with treatment decisions that have uncertain outcomes. Today’s choice may turn out to be better than, equal to, or not as good as others taken.

Mishel's theory states that uncertainty is natural and an inherent part of reality. Accepting uncertainty opens doors to consider multiple possibilities, because nothing is certain or universal. It also can remove barriers to trust and can help patients and their families feel more comfortable with the decision-making process.

Janet Stewart, PhD, RN, assistant professor in the Department of Health Promotion and Development, is studying how children and their families adjust to cancer and cancer treatment. With funding from the ONS and Amgen Inc., Stewart developed a measure of uncertainty in children, based on Mishel's theory on uncertainty in illness.

Stewart is working collaboratively with nurse scholars from the Children's Hospital of Pittsburgh of UPMC oncology group to study parental treatment decision making. Her goal is to develop and test interventions to help manage uncertainty in young children and their families.

**How, and what, do you tell your family if you decide to have genetic testing and the results are positive?**

Rebekah Hamilton, PhD, RN, assistant professor in the Department of Health Promotion and Development, is studying what individuals and their families do with predictive genetic testing information. With funding from the NIH, Hamilton is looking at the long-term consequences of a decision to have genetic testing—how people deal with genetic test results and what decisions they make after testing.

Young women with breast cancer generally have many relatives with breast cancer. Mutations on two specific genes (BRCA1 and BRCA2) have been shown to increase the risk for breast and ovarian cancer, but not all women with a family history of breast or ovarian cancer have one of these mutations, and not all women with one of these mutations will develop cancer. Genetic testing could identify women who should consider intense cancer screening or procedures to reduce cancer risk (medication or surgical removal of breasts, ovaries, or both). However, since not all women who have these mutations develop cancer, identifying these mutations may also needlessly expose women to anxiety, insurance problems, or unnecessary procedures.

“What must it be like to be 20 and thinking about having a prophylactic mastectomy?” Hamilton wonders. She is asking young women ages 18–35 what (and who) influences their healthcare decisions after genetic testing for the BRCA mutations. Preliminary results reported at the International Society of Nurses in Genetics conference in October 2005 in Salt Lake City, Utah, indicate that healthcare decisions for these young women are complicated by all of the normal developmental issues that come with being 18–35—relationships, reproduction, family, and career. For example, there is some evidence that younger women may get more pressure from their fathers. A compelling finding from her research so far is that younger women report having few resources to help guide them once they get their genetic testing results.

One of Hamilton's goals is to develop an intervention that will provide young women with the resources they need to make decisions and help guide them through the complex issues of being young and at risk for hereditary breast and ovarian cancer.

**Oncology Researchers** at the School of Nursing share a common goal to improve outcomes, quality of life, and care for cancer patients and their families.
“In my genetics class, students are surprised to learn that every cancer cell has a genetic abnormality.”
GENETICS

PATIENT PROGNOSIS AND TREATMENT CAN BE TAILORED BY IDENTIFYING GENETIC ABNORMALITIES

YVETTE CONLEY, assistant professor, Department of Health Promotion and Development

GENETICS RESEARCH AT the School of Nursing started in 2000. Two notable firsts illustrate the enormous growth of genetics research at the School since that time.

Under the direction of Yvette P. Conley, PhD, assistant professor in the Department of Health Promotion and Development, the School opened the first fully functional genomics laboratory to be located in a school of nursing. This state-of-the-art laboratory serves as a model for other schools of nursing and is a resource for students and faculty both at the school and the University. “People who come to the lab are always impressed not only with the equipment, but also with the size of the lab,” Conley says.

The School is also the first nursing school to require a full semester of genetics. “In my genetics class, students are surprised to learn that every cancer cell has a genetic abnormality,” Conley says. “This is part of the reason why genetics has had some of its biggest impact on oncology research.”

Genetics nursing research impacts patient care. Identifying a specific genetic abnormality enables healthcare providers to tailor a patient’s prognosis and treatment. For example, abnormalities involving the Her2 gene can be identified in approximately 25 percent of breast cancers. Knowing this affects prognosis because a breast cancer with a Her2 gene abnormality is often more aggressive. This knowledge also affects treatment because Herceptin, a drug tailored to combat this particular type of genetic abnormality in the cancer cell, has proven to be effective in fighting the disease. “Genetics research has the potential to identify other individuals who may be at risk and tailor treatment regimens targeted to specific abnormalities,” Conley says.

WHY DO SOME PEOPLE age better than others? Information about the genetics of aging will help researchers understand the biology of individual variation in the aging process. Studying genetic differences in aging is of particular interest because while our lifespan has been increasing, our health span has not kept up. In a study funded by the National Institute on Aging, Conley is looking at the genetic factors that influence the pace of aging. Her research will help identify the mechanisms of longevity and have an impact on improving the health span of individuals.

CONLEY BELIEVES the difference in recovery from a traumatic brain injury (TBI) can be traced to genetics. Nearly 2 million Americans suffer from TBI each year. Damage from the initial trauma poses an immediate threat, but subsequent events often cause secondary injury. There is considerable variation in functional outcome attained after a TBI, even when other
“Genetics researchers want to help patients and improve patient care,” Conley says. “Nurses are especially well suited for genetics research because it is a perfect match of science, compassion, and evidence-based care.”

factors are similar between individuals. Determining what is responsible for this variation could aid healthcare providers in maximizing outcomes following a TBI. Funded by the National Institute of Nursing Research (NINR), Conley is studying the mitochondrial genetics of recovery after brain injury.

SHEILA ALEXANDER, PhD, assistant professor in the Department of Acute and Tertiary Care, is looking at genetic-based susceptibility to cerebral vasospasm (CV), a decrease in the size of the cerebral blood vessels that increases risk of stroke, after subarachnoid hemorrhage (SAH)—a bleed into the area around the brain—and is associated with poorer outcomes after SAH. Although up to 40 percent of all individuals recovering from SAH will have CV, there are few mechanisms to monitor for development of CV and no biomarkers to identify individuals at risk for CV. “I want to find ways to identify individuals at risk of having poor blood flow to the brain after neurologic injury, and then someday find ways to improve that blood flow,” Alexander says. “If a genetic-based biomarker is identified, it could allow for the early identification and treatment of CV.” Alexander also is exploring other genetic influences on recovery from SAH as well as TBI.

A LIFELONG GENETIC EPIDEMIOLOGIST, Janice S. Dorman, PhD, MS, associate dean for scientific and international affairs and professor in the Department of Health Promotion and Development, focuses her research on autoimmune diseases, specifically women’s health and type 1 diabetes. In collaboration with co-investigators at Children’s Hospital of Pittsburgh of UPMC, the University of Pittsburgh, and UPMC, Dorman is studying “Genetic Studies of Diabetes: Technology to Improve Prediction and Prevention of Disease,” also known as the GIFT-D project.

Dorman knows that the speed at which genetic testing has become available is rapid, but one area of concern is whether the patient is truly informed about what the genetic testing means. With Denise Charron-Prochownik, PhD, RN, associate professor in the Department of Health Promotion and Development, she identified the gap in education and genetic testing availability. Dorman and Charron-Prochownik noticed that families agreed to be tested for type 1 diabetes without full knowledge of what a genetic test for diabetes susceptibility can look for, and what the test is unable to reveal. The research team developed computer-based education modules to help family members understand the relationship of genetics and make an informed decision about having genetic testing. The research team also developed genetic education modules to help healthcare professionals describe the genetic test and explain the ramifications of learning about their results to their patients. Their ultimate goal is to have the modules available for Web-based education.

WHAT DO YOU DO when you get the results of genetic testing? Rebekah Hamilton, PhD, RN assistant professor in the Department of Health Promotion and Development, is interested in the genetic impact of oncology. In a project sponsored by the NINR, she is studying the health-behavior decision making in young women who discover they are at high risk for hereditary breast and ovarian cancer. Young women with a positive BRCA genetic mutation face a potentially deadly legacy at a developmentally critical time in their lives. This study will describe how receiving genetic risk information affects decisions about actual health behaviors.

“It is important for nurses to be involved in this type of research because genetic testing is ahead of the education of patients,” Conley says. “Nurses have compassion when administering the test and make sure the patient understands what the test means.”

AS A NURSE ANESTHETIST, Rich Henker recognizes that patients undergoing surgical procedures have inconsistent responses to pain treatment. Henker, PhD, RN, associate professor and vice chair in the Department of Acute and Tertiary Care, is studying genetic differences in pain response. Identifying genetic differences before surgery may help healthcare providers determine safer and more effective opioid requirements for patients.

In a study sponsored by the American Association of Nurse Anesthesists Foundation, Henker is exploring
the relationship of mu receptor genotype and gender with postoperative pain response and the amount of opioid administered.

Lora Burke, PhD, RN, associate professor in the Departments of Epidemiology and Health and Community Systems, recently received funding to follow a cohort of participants from one of her weight-loss studies. Burke and Conley will explore whether variation in genes known to influence the risk of developing obesity are related to weight fluctuations, how body fat is distributed, and the development of insulin resistance and atherosclerosis.

Preeclampsia affects 5 percent to 8 percent of all pregnancies. Characterized by high blood pressure and the presence of protein in the urine, this rapidly progressive condition affects both the mother and the unborn baby. Preeclampsia and other hypertensive disorders of pregnancy are a leading global cause of maternal and infant illness and death.

Sandra Founds, PhD, RN, assistant professor in the Department of Health Promotion and Development, thinks there may be a genetic explanation as to why some women develop preeclampsia and others do not. Founds is investigating genetic studies of preeclampsia to determine whether there is altered gene expression in early placental development in women who develop preeclampsia.

Susan Albrecht, PhD, RN, FAAN, associate dean for student and alumni services and associate professor in the Department of Health and Community Systems, focuses her research on prevention of smoking relapse in the postpartum period, a critical time for women who quit smoking during their pregnancy. As part of her research, Albrecht is investigating genes thought to influence smoking behavior and nicotine metabolism. This information may help tailor the most effective smoking relapse prevention program for an individual.

“Genetics researchers want to help patients and improve patient care,” Conley says. “Nurses are especially well suited for genetics research because it is a perfect match of science, clinical expertise, and potential for translation to healthcare.”

The Center for Research in Chronic Disorders (CRCD) is an independent entity in the School of Nursing that supports multidisciplinary, outcomes-based adherence research in chronic disorders through five central interdependent cores:

- **Administrative Core**: Provides administrative oversight and coordinates support services to promote collaboration and integration within the broader scientific community.

- **Data Management and Analysis Core**: Supports common methods of data management and statistical analysis of adherence and clinical outcomes.

- **Cognitive Core**: Designs and creates tailored test batteries to measure psychological and cognitive function as they may impact treatment adherence.

- **Research Development Core**: Pilot funds are provided for internal and external investigators to foster research of the management of treatment regimens in persons with chronic disorders. Through monthly visiting scholars’ presentations, the core brings national and international experts on adherence research to stimulate multidisciplinary collaborations throughout the University. Monthly journal club sessions foster discussion among doctoral students and faculty on topics pertinent to the CRCD’s mission.

- **Dissemination and Translation Core**: Information and research findings are disseminated through the *Chronicle*, a quarterly publication, and patient and provider newsletters. Findings are translated into practice through conference seminars and workshops with clinicians.

The CRCD was established in October 1994 with a five-year grant from the National Institutes of Health/National Institute of Nursing Research (2 P30 NR003924-11), and is one of only three centers in the United States to have been continually funded since 1994. During its first 10 years, the CRCD focused on the effects of chronic illness, health disparities, and socio-demographic characteristics on quality of life, functional status, cognitive function, and adherence to treatment regimens. The work of the past decade identified the central role that adherence to management guidelines plays in clinical outcomes. Current CRCD projects focus on interventions to improve adherence to medication and lifestyle changes such as weight-loss and exercise regimens.
CRITICAL AND END-OF-LIFE CARE

Critical Care Nurses direct patient care from the acute event, through palliative care, to the end of life. Researchers at the School of Nursing are studying health disparities, neurology, genetics, oncology, and pulmonary dysfunction across the continuum of acute care services.

How do outcomes compare when advanced care nurse practitioners (ACNPs) manage patient care in a critical care setting? In a study funded by the National Institutes of Health (NIH), Leslie A. Hoffman, PhD, RN, FAAN, professor and chair of the Department of Acute and Tertiary Care, compared outcomes between ACNP and housestaff (physicians who are completing a fellowship in pulmonary or critical care medicine) who managed patient care in a medical intensive care unit. Hoffman’s study showed that patient outcomes were equivalent with one exception—more patients required reintubation (replacement of the breathing tube) under care of housestaff. Hoffman and her team believe the greater continuity of care under ACNP care may explain this outcome. In companion studies, her research team documented that ACNPs and housestaff require a similar amount of time to manage patient care, and a qualitative analysis of the perceptions of intensivists, respiratory therapists, and nursing staff concluded that ACNPs are valued for their contributions to medical management in critical care settings.

Approximately 13,500 Americans die each year from subarachnoid hemorrhage (SAH), a form of stroke where blood enters the space surrounding the brain. SAH affects 30,000 Americans each year and has a mortality rate of 45 percent. The primary cause of this high mortality rate is cerebral vasospasm (CV), a condition where the cerebral blood vessels contract for prolonged periods, causing a decrease in delivery of blood and nutrients to the brain. In a second study funded by the NIH, Hoffman is testing whether a biomarker (20-HETE) influences development of CV after SAH and whether the extent of CV during the first 14 days after injury predicts functional recovery.

Sheila Alexander, PhD, RN, assistant professor in the Department of Acute and Tertiary Care, also is interested in SAH. In a study that combines genetics research with critical care research, Alexander is examining the influence of Apolipoprotein E genotype (common variations in gene) and phenotype (differences in amounts and forms of proteins) on both short- and long-term recovery after SAH. The ability to identify individuals at risk for CV and poor outcomes will enable intensive care unit nurses and other healthcare professionals to provide individualized interventions to maximize recovery and focus resource utilization on individuals at the greatest risk. Alexander also is exploring other genetic influences on recovery from SAH as well as traumatic brain injury.

Coronary Heart Disease (CHD) is the second leading cause of hospitalization in America. More than 12 million people in the United States have CHD, but the death rate from this disease is higher among African Americans than for any other racial or ethnic group for which data are recorded. Coronary artery bypass grafting (CABG) is a common invasive intervention used to treat CHD, but African Americans are less likely to undergo CABG than Caucasians with equivalent severity of disease, and they experience higher postsurgical morbidity and mortality.

Marilyn Hravnak, PhD, RN, CRNP, associate professor in the Department of Acute and Tertiary Care, is studying
CRITICAL CARE NURSES IMPACT THE CONTINUUM OF PATIENT CARE THROUGH RESEARCH.
Respiratory tract intubation for airway management can be a traumatic life event. Patients may be frightened because the tube makes it impossible for them to speak. It further reduces their ability to participate in their own care and decision making. And it impairs pain and symptom assessment for the healthcare providers. One patient on long-term mechanical ventilation expressed her thoughts by writing them down because she could not speak. “I’m afraid I’ll be living when I want to be dead,” she wrote.

Mary Beth Happ, PhD, RN, associate professor in the Department of Acute and Tertiary Care, understands how important communication is with ventilated patients. In a study funded by the National Institute of Child Health and Human Development, Happ is developing tools to improve communication with nonspeaking intensive care unit patients—communication tools to enhance the quality of their lives and remove one of the barriers to participating in decision-making processes that affect their health and outcomes.

Many people are afraid of receiving unwanted treatment at the end of life. Despite the increasing emphasis placed on patient-clinician communication about end-of-life care, efforts to guide the patient to make an informal end-of-life treatment decision often fail.

Mi-Kyung Song, PhD, RN, assistant professor in the Department of Acute and Tertiary Care, wants to improve communication with critically ill patients. Song’s research is focused on improving end-of-life care with better end-of-life communication and decision making.

Song is studying end-of-life communication among African American patients who have end-stage renal disease. In this study, Song is testing an hour-long intervention, patient-centered advanced care planning, to see whether communication about end-of-life care improves between clinicians, patients, and their surrogate decision makers.

Song also is studying the final stages of illness after chronic lung rejection. Transplantation has become a viable treatment option for patients with end-stage lung disease, but the long-term outcomes of this procedure are limited. Post-transplant management currently focuses on aggressive immunosuppression to prevent rejection of the transplanted organ, antimicrobials to prevent opportunistic infections, and surveillance programs to detect and treat complications after transplant. But these approaches have not been successful in preventing the pervasive complication of chronic rejection. There is no cure for chronic rejection, and the only current treatment option is retransplantation. With funds from the School of Nursing’s Center for Research & Evaluation, Song is exploring how lung transplant patients manage their illness from the onset of chronic rejection until death.

These studies facilitate better forms of care at the onset of critical illness, improving the rate of recovery, and improving communication during critical illness and end-of-life decision making.
ADHERENCE IS A CONCEPT

ADHERENCE OR COMPLIANCE is how well individuals follow their prescribed treatment plan. It is the key to self-management, enabling individuals to manage their own health. But current research demonstrates there is significant noncompliance with behavioral as well as pharmacologic treatment regimens, particularly among the elderly.

Individuals with chronic disorders may need to follow a treatment regimen for the rest of their lives. And many people take some sort of medication on a daily basis: vitamins, calcium, or some other over-the-counter or prescription medicine to treat a condition. The challenge is remembering to take it. For the elderly or individuals with comorbidities (one disease in coexistence with other diseases or conditions), that challenge may be compounded by complex treatment regimens that are difficult to follow—a complex regimen might include a daily or weekly exercise component and multiple medications to be taken at different times of the day.

Researchers at the School of Nursing hope to make adherence easier. Easier to remember to take medication. Easier to comply with regimens of physical activity to improve functioning. Easier to follow and stay on a diet regimen. Easier to self-manage. Ultimately, all intervention studies focus on improving health and quality of life.

There can be many other barriers to adherence—social, economic, physical, or psychological—or patients simply may not understand the regimen or how to implement it. In one study, a patient complained that her inhaler didn’t work. The nurse walked the patient through the process to identify a solution to the problem. The patient did everything perfectly, except she forgot to remove the cap from her inhaler. Everything else was fine, but she missed a crucial step.

In another study, a patient did not fill his prescriptions because he could not afford the medication—a preadherence obstacle. Or, a patient might not like the taste or side effects.

Another patient forgot to take his nighttime pills when he fell asleep in front of the TV. Other patients pocket-dose—they measure out the medications they need for a day, but forget to follow through when they get busy or while they are at work. So, the medications are not as effective as they should be.

Memory may be only one barrier in behavioral treatment regimens. Motivation, pain, and fatigue can make patients resistant to regimens of diet and exercise. Before we can identify interventions to enable people to better adhere to treatment regimens, we need to understand the complexities of adherence.

JACQUELINE DUNBAR-JACOB, PhD, RN, FAAN, dean of the School of Nursing; professor of nursing, epidemiology, and occupational therapy; and director of the Center for Research in Chronic Disorders (CRCD), has studied medication adherence for more than 20 years. She is working with patients who have type 2 diabetes in combination with other health problems, such as high cholesterol and high blood pressure levels, to learn how people handle taking multiple medications when they have multiple disorders requiring medication.

JUDITH A. ERLEN, PhD, RN, FAAN, professor in the Department of Health Promotion and Development, doctoral program coordinator, and associate director of the CRCD, has been conducting intervention studies with patients who have HIV infections for approximately eight years. Weekly telephone calls by nurses encourage patients to improve their medication regimen. In addition to the phone intervention, these studies employ diaries and medicine bottles fitted with a special cap that records the date and time the bottle is opened. All the patients in these studies are asked to use a diary so they can record how they are taking their medicines.
Before we can identify interventions to enable people to better adhere to treatment regimens, we need to understand the complexities of adherence.

Judith A. Erlen, PhD, RN, FAAN

The goal of these telephone interventions is to enable people to become more adherent to medication taking so their clinical outcomes and quality of life improve. One patient who had been extremely nonadherent said, “I see now how far I have really come.” Prior to the intervention, this patient’s health problem had been out of control. By managing his medication more carefully, his health has improved.

Findings from this work have been presented at the Eastern Nursing Research Society, Sigma Theta Tau, and the Society of Behavioral Medicine. Although adherence did not improve as much as the researchers expected, the interventions did demonstrate modest changes in adherence for patients with HIV infections.

IMPROVING LONG-TERM weight loss is the goal of a study conducted by Lora E. Burke, PhD, MPH, RN, associate professor in the Departments of Epidemiology and Health and Community Systems. Funded by a grant from the National Institute of Diabetes and Digestive and Kidney Diseases, Burke is looking at the correlation between adherence to recording food intake and physical activity and weight loss. She uses a variety of paper and electronic diaries to have patients record what they are eating and when. One of her studies is discussed further on page 20. Patients in her study report that the act of recording makes them feel more in control.

Diaries in one form or another are a common way to collect data in adherence studies. Burke asks people what they are doing that hurts them, then asks them to write down when they are doing it so the individuals can monitor their own behavior. She is doing pilot work to improve how people self-monitor and make patients more aware of their own behavior. Initial results show that electronic diaries and personal digital assistants can improve self-monitoring by making recording easier and more effective.

SANDRA J. ENGBERG, PhD, RN, CRNP, assistant professor and chair in the Department of Health Promotion and Development, is examining the effectiveness of a relapse intervention to improve long-term adherence to pelvic floor muscle (PFM) training for urinary incontinence in older adults. Biofeedback is used to teach participants PFM exercises and how to actively use their PFM to prevent involuntary urine loss. The relapse intervention is designed to help participants identify and deal with barriers to doing their exercises. Adherence is measured by both self-report and by bladder diary where subjects record each time they do their prescribed exercises.

A PRIMARY NATIONAL HEALTH GOAL, identified in Healthy People 2010, is to increase the proportion of adults who engage in moderate physical activity for at least 30 minutes each day. This is particularly important in individuals with cardiovascular risk. One barrier to physical activity in this population is osteoarthritis of the knee. Only 15 percent of persons with osteoarthritis participate in regular physical activity.
Researchers at the School of Nursing are engaged in both clinical and basic science research. By addressing some of the most challenging issues facing today’s healthcare practitioners, they provide a scientific basis for the care of individuals across the life span. In addition, they prepare and develop future generations of nurse researchers.

The Center for Research & Evaluation (CRE) was established in the fall of 1987 to help meet the School’s growing commitment to research. The CRE has a full complement of biomedical and data laboratories stocked with state-of-the-art equipment. In addition, a staff of statisticians, grants administrators, and clerical personnel offer support services such as:

- Data analysis, design, and consultation.
- Training in data design and management.
- Budget development and monitoring.
- Scientific review of proposals.
- Oversight of project compliance with sponsor and internal requirements.
- Proposal packaging.
- Maintaining project funding.
- Disseminating information about opportunities for funding, training, development, conferences, and research.
- Developing faculty and doctoral student research methodology.
- Consulting on the development of research programs.

Elizabeth A. Schlenk, PhD, RN, assistant professor in the Department of Health and Community Systems, is studying adherence to exercise programs in individuals at cardiovascular risk who also suffer from osteoarthritis of the knee. Osteoarthritis of the knee can be managed through a program of quadriceps strengthening and graduated walking, yet only half engage in these exercises. Addressing osteoarthritis of the knee is a first step to developing a regular physical activity program among older adults at cardiovascular risk.

Schlenk’s study is a 24-week intervention in combination with self-report. An electronic pedometer was one of the tools used to measure adherence. The intervention also included six individualized weekly sessions with a physical therapist followed by nine biweekly telephone counseling sessions with a nurse. She has found that by moving their joints a little bit better, people are able to improve physical functioning and walk farther.

Arthritis is a common problem for many people as they grow older. Schlenk’s findings have potential impact for a broader population.

In each of these studies, researchers have seen how difficult it is to self-manage long-term behavior, so they are studying maintenance strategies and booster programs to sustain adherence. They also are developing studies to target specific factors that can impede or enhance adhering, such as social support, cognitive function, and personality.

One patient who had been extremely nonadherent said, “I see now how far I have really come.”
APPLICATIONS FOR TECHNOLOGY cross all health disciplines. Nurses focus on the development and application of technologies that enhance the quality of life for people with acute or chronic illness and their families. For technology to be useful it must be patient-centric—that is, it must serve the real needs of patients and fit seamlessly with their daily lives.

Several exciting areas of study at the University of Pittsburgh School of Nursing are involved in expanding existing technologies or developing emerging technologies. But, nurses don’t do any of it alone—they lead multidisciplinary teams, and projects are inter-institutional as well as interdisciplinary.

Like the design of any technology, there are three principles that guide the design of patient-centric technologies. First, recognize a consumer health need. Next, identify technology that can meet that need and empirically measure its functionality. Then, refine the idea, fix the technology, test it, get input from potential users, and then go back again. It is an iterative process that can be time-consuming and costly.

THE LIFELONG, complex medical regimens required to prevent organ rejection after transplantation are difficult for many patients to follow. Annette De Vito Dabbs, PhD, RN,
assistant professor in the Department of Acute and Tertiary Care, is developing technology to help.

For individuals with end-stage lung disease, a lung transplant offers the only hope for extended survival and improved quality of life. But transplantation is not considered a cure; it is an exchange of one chronic illness for another. While most lung recipients experience dramatic improvements in their overall health, they also can face a variety of lung complications, such as acute and chronic rejection, and infection. In addition, the lifelong immunosuppression regimen that transplant patients require can result in many other complications.

As a result, lung recipients typically experience a course of gradual decline punctuated by episodes of acute complications. Each complication leads to setbacks, greater morbidity, and disability. Patients must follow complex medical regimens to control their underlying illness and reduce the frequency and severity of complications. “Maintaining longer intervals without complications enables lung recipients to experience a more satisfying level of functioning and ‘normalcy within illness,’” De Vito Dabbs says.

**Funded by the** National Institute of Nursing Research and the University of Pittsburgh Central Research Development Fund, De Vito Dabbs is collaborating with the Human Computer Interaction Institute at Carnegie Mellon University to design and pilot-test an interactive handheld technology-based intervention called Pocket PCs to Promote After-Transplant Health (PocketPATH).

PocketPATH is a practical tool that can help lung recipients prevent and detect acute complications. Customized data recording, tracking, messaging, and decision-support programs help lung transplant recipients adhere to their medical regimens, record and interpret trends in their self-monitoring data, detect potential adverse conditions, and communicate changes to the transplant team.

The success of PocketPATH will be judged on how well lung recipients like and use the device and on how well its use leads to reduced morbidity, disability, and healthcare resource utilization after lung transplantation. If it is successful, PocketPATH will pave the way for future applications in other transplant and chronic illness populations.

**Mary Beth Happ, PhD, RN,** associate professor in the Department of Acute and Tertiary Care, is working on two studies to understand and improve communication with non-speaking patients in acute and critical care settings.

The first study, funded by the Oncology Nursing Foundation and the American Association of Critical Care Nurses, looked at how people intubated for mechanical ventilation following head and neck surgery respond using an Augmentative Assistive Communication Device (AACD). Patients who are unable to speak can express their feelings, wants, and needs through an electronic speech-generating communication board. Happ looked at the content, quality, and frequency of communication, as well as patient satisfaction when 21 nonspeaking hospitalized patients were given these devices. The study showed that selected seriously ill, hospitalized patients can use these devices to express themselves as long as the device is matched to the patient’s abilities, is within reach, functions properly, and there is knowledgeable staff.

“I love you” was the most frequent communication intubated patients used to express their feelings to others around them—particularly family.

That study led to the Study of Patient-Nurse Effectiveness with Assisted Communication Strategies (SPEACS), a multidisciplinary clinical intervention trial. In conjunction with investigators at the University of Pittsburgh, Duquesne University, and UPMC, this study—funded by the National Institute of Nursing Research and the University of Pittsburgh Central Research Development Fund—will pave the way for future applications in other transplant and chronic illness populations.
Institute of Child Health and Human Development—looks at communications between nurses and nonspeaking intensive care unit (ICU) patients. This study is testing the impact of providing nurses with (1) basic communication skills training and (2) consultation by a language pathologist on the use of augmentative and alternative communication techniques.

In a series of observations videotaped over several years, Happ is looking at the communication between 30 nurses and three nonspeaking ICU patients each, for a total of 90 patients. The communication interactions on these tapes are coded and analyzed. To establish a benchmark, Happ first looks at tapes of the nurse-patient interactions during usual care before the intervention. After nurses receive communications skills training developed by the research team, the patient-nurse communication will be taped again. In the third step, nurses will receive individual counseling from a language pathologist and training in the use of AACDs.

Happ’s study provides an objective measurement of how the quality and nature of communication between nurses and nonspeaking patients in the ICU changes with increased levels of information, skill sets, and the addition of AACDs.

**Obesity is a chronic** disorder with a high rate of recidivism. Lora E. Burke, PhD, MPH, RN, associate professor in the Departments of Epidemiology and Health and Community Systems, is developing tools to help patients lose weight—and keep it off.

Self-monitoring is the cornerstone of behavioral treatment. Documenting and following their behavior and responses is important for patients who are trying to lose weight, and is a strong predictor of their long-term weight-loss success. But studies show that adherence to those positive health behaviors may wane over time.

Burke’s studies on obesity and weight loss look at self-monitoring, and ways to improve self-monitoring by making it more timely and less time-consuming as patients go through the many-times-daily habit of eating. In two studies with investigators at the University of Pittsburgh, Stonybrook University in New York, and Emory University, funded by the National Institute of Diabetes and Digestive and Kidney Diseases, Burke is examining a variety of approaches to determine which ones are most effective for individuals tracking their own food consumption and physical activity.

In an earlier study that looked at patterns of self-monitoring, Burke found that weight loss is significantly related to frequency of self-monitoring and marginally related to recording within two hours of eating. The study concluded that timeliness is important and related to outcome.

Burke has been working with a company to develop software for a personal digital assistant (PDA) that will track when recording occurs and also will make self-monitoring easier. The PDA being used to track self-monitoring does more than keep track of when the patient records. The recently developed dietary software program provides a database of more than 6,000 foods and calculates the calorie and fat content of foods consumed, and displays these values. Meanwhile, the physical activity program tracks the patient’s daily physical activity and exercise. This information makes it easier and more convenient for people to self-monitor how they are doing in relation to their daily goals for calories and fat grams as well as their weekly goals for physical activity.

In a further refinement of her intervention study, Burke is measuring the effect of adding messages to the PDA that provide individuals with feedback on how they are doing. Burke’s studies have expanded quite a bit from the simple paper diary enabling people to see what they have actually done as opposed to what they have set for target goals. Burke will be presenting a paper at the Society of Behavioral Medicine’s annual conference in 2006 on her latest findings pertaining to self-monitoring and success in weight loss.

Losing weight and keeping it off is difficult, but Burke is finding ways to help individuals succeed.
THE GREATEST CHALLENGE as people age is to keep their independence. As they get older, adults may develop geriatric syndromes and multiple chronic disorders with complex treatment regimens to follow. Judith Matthews, assistant professor in the Department of Health and Community Systems, is working on two studies to develop mobile robots capable of monitoring and guiding the daily activities of elderly people, and enabling them to sustain independent living.

The NurseBot project is an interdisciplinary multi-university research initiative focused on developing robotic technology for the elderly. Initially funded by the National Science Foundation, this study brings together researchers from the University of Pittsburgh, Carnegie Mellon University, the University of Michigan, and Stanford University.

Specifically, the NurseBot project is developing two mobile personal-service robots that assist elderly people suffering from chronic disorders in their everyday lives. In a study funded by the National Institutes of Health, the current prototypes—Pearl, a humanoid robot; and the IMP (Intelligent Mobility Platform), a robotic walker—are undergoing preliminary usability testing in field studies with older adults.

The two robots provide research platforms to test a range of ideas for assisting elderly people, such as:

- Intelligent reminding: Many elderly patients have to give up independent living because they forget. The robot can remind people to visit the restroom, take medicine, drink, or see the doctor.
- Tele-presence: Professional caregivers can use the robot to establish a “tele-presence” and interact directly with remote patients.
- Data collection and surveillance: Systematic data collection can help avoid a range of emergency conditions such as certain types of heart failures.
- Mobile manipulation: Arthritis is the main reason for the elderly to give up independent living. A semi-intelligent mobile manipulator can help older adults overcome some barriers that currently force patients to move into assisted-living facilities.
- Social interaction: Too many elderly people are forced to live alone, deprived of social contacts. The project is exploring whether robots can take over certain social functions.

If successful, this project could change the way we deliver healthcare to the ever-growing contingent of elderly people, and it could significantly advance the state of the art in mobile-service robotics and human-robot interaction.

THESE PROJECTS all employ patient-centric technology as a tool to enhance the quality of life for people with acute or chronic illness and their families. Nurse researchers are well suited to identify patient needs that can benefit from technology solutions and assure that the resulting products fit seamlessly with their daily lives.

INDEPENDENCE IS HAPPINESS.

Susan B. Anthony
INFORMATICS

NURSING INFORMATICS is a combination of information science and nursing science. Nursing informatics includes the development, analysis, and evaluation of information systems that support, enhance, and manage patient care. The emphasis within the School of Nursing is consumer informatics.

Several studies at the School of Nursing are looking at improving provider-family/patient communication, increasing enrollment in clinical trials, and evaluating the quality of healthcare information. The common goal of all these projects is to improve patient outcomes.

The Caring Connection is in the final step of a four-phase project. In the first phase, Lewis researched how parents use the Web for information and communication. She and her team then built prototypes and pilot-tested them with families. In the third phase, the team redesigned and pilot-tested the Web site again, iteratively changing the portal to better meet the needs of the families. Now, in the final phase, the site has been implemented.

The site has several family-friendly features, including tips about talking to your clinician when you come to the hospital. The three major components to the site are a health almanac, information resources, and a gathering place:

- A health almanac captures actual clinical data including laboratory results, treatment protocols, and current medications with links to drug information sheets developed at Children’s Hospital of Pittsburgh of UPMC.
- The information resources section includes a glossary, information about cancer types and drugs, links to validated/qualified Internet resources, and a link to the Children’s Hospital library. This section also includes information specific to kids and their siblings.
- The Gathering Place is a discussion board that sits on a secure server, providing parents with a safe, secure means to communicate with providers about lab studies.

DEBORAH LEWIS, EDD, MSN, associate professor in the Department of Health and Community Systems, is building a better Web portal for families of children with cancer. Initial research shows that 89 percent of parents surveyed look up health information on the Internet. The Caring Connection is a family-focused communication and information resource designed to extend the process of family-provider communication beyond the clinical setting into the parent’s home and community.