

REMOVING UNCERTAINTY FOR CANCER PATIENTS AND SURVIVORS

Nurse scientists at the UNC Chapel Hill SON are at the forefront of research that is helping cancer patients.

Cancer has a life-changing effect on the person diagnosed as well as his or her family. Big decisions must be made about treatment, and stress can come from uncertainty around cancer recurrence, side effects from treatment or from conditions that may arise many years after treatment has ended.

Researchers at the UNC Chapel Hill School of Nursing help cancer patients and survivors by creating and testing interventions that help diminish their uncertainty. In addition, nurse scientists are improving personalized information tied to cancer risk factors and are exploring new technology for delivering interventions.

Dr. Merle H. Mishel, Kenan Professor of Nursing and the director of doctoral and post-doctoral programs, and Dr. Barbara Germino, professor and the first Carol Ann Beerstecher-Blackwell Distinguished Professor of Health Care, developed an intervention that reduced uncertainty that prostate cancer patients have upon initial diagnosis. The work was funded by the National Institute of Nursing Research at the NIH.

“Traditionally a patient receives a diagnosis of prostate cancer and then comes in immediately for a treatment decision, but he doesn’t really understand what is happening,” Dr. Mishel said. She developed the theory of uncertainty in illness, which refers to the patient’s ability to understand the illness situation, to provide meaning to the situation and to participate productively with the physician in a plan of care. Mishel’s theory is used and studied around the world and was the basis for the intervention for the prostate cancer patients. “We wanted to really increase their knowledge,” she said. “We wanted to produce a competent patient.”

The doctors modified their normal protocol for this study,

allowing about a week for the intervention before discussing treatment options with the patient. Either the patient only or the patient and his primary support person received the intervention. A control group received no intervention.

The research protocol included the patients receiving the booklet *Treatment Choices for Early Stage Prostate Cancer: Patients’ Questions — Doctors’ Answers*. It had ten sections, each with topic-specific questions and brief answers covering a topic such as understanding prostate cancer or treatments. Patients noted questions for their physician in a tear-out sheet at the back of the booklet. A DVD given to the study participants presented scenarios in which patients talked with their doctors about treatment options and was designed to improve communication skills. In addition, subjects or subjects and their primary support persons received four calls, during which intervention nurses did things such as answer questions about the book’s content, helped the patient develop specific questions based on his concerns, and reviewed and practiced the DVD’s communication skills.

The intervention proved helpful for the patients, and it was most beneficial when the patient and his primary support person received the intervention, Dr. Mishel said. Men who received the intervention improved in uncertainty management, cancer knowledge, problem-solving, patient-provider communication and competence in medical communication. These men also had a significantly lower level of decisional regret.

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Dr. Mishel (right) and Dr. Germino (left) developed an intervention for prostate cancer patients that removes some of the uncertainty that occurs just after diagnosis.

The researchers concluded that before deciding about treatment, patients and supportive others need information about the disease, treatment options and side effects as well as communication skills training. “We must give the patients some information before they go in to decide about treatment,” Dr. Mishel said.

CHILDHOOD CANCER SURVIVORS

Uncertainty plays a different role in cancer survivors than it does in patients just diagnosed with cancer, and this uncertainty presents later in life for those who survived childhood cancer. Dr. Shelia Santacroce, associate professor and the current Beerstecher-Blackwell Distinguished Professor of Health Care, is studying adolescents and young adults who survived childhood cancer.

Survival rates associated with childhood cancer have increased greatly in the last decade. However, this success can bring health problems that stem from cancer treatments. Once children are old enough to understand the fatal nature of their

childhood disease and the ongoing implications for their future health they can develop post traumatic stress symptoms, such as nausea or a racing heart, that are triggered when returning to the hospital where they received treatment. Or they may have a sense that their future is foreshortened and thus take risks with their health and not adopt healthy lifestyle behaviors.

Often, cancer survivors feel highly anxious due to uncertainty about whether they will develop a second cancer or another serious health condition that can be attributed to the curative treatment they received. Santacroce has developed and tested an intervention aimed at helping adolescent and young adult cancer survivors and their parents think more positively about uncertainty surrounding health conditions that can arise later in life because of the cancer treatments.

“We wanted to help our young cancer survivors shift their view of the health education we offer in long term follow-up care from scary to empowering,” she said. “When survivors know what potential problems they face, they can take actions to protect and monitor their health rather than waiting until they develop symptoms.”

During the testing of the interventions, the adolescents and their parents received eight phone interventions designed to improve coping through anxiety-reducing communication skills and a systematic process for problem solving.

In Dr. Santacroce’s research, which was supported by a grant from the NIH National Cancer Institute, 80% of the parent participants had moderate-to-severe post traumatic stress symptoms.

This finding highlights the importance of including parents and other close family members in oncology nursing research and clinical care.

Dr. Santacroce and her research team recently performed a pilot study looking at whether uncertainty and other sources of chronic psychological stress lead to cardiovascular disease in childhood cancer survivors. The researchers wanted to determine if there is an important physical or medical outcome



Dr. Santacroce is studying the relationship of uncertainty and other sources of chronic psychological stress to developing cardiovascular disease in childhood cancer survivors.

that can be linked to uncertainty and chronic psychological stress. The cancer survivors are already at risk for future heart problems because of cancer treatments they received, and Dr. Santacroce seeks to find out if that risk is increased because of chronic psychological stress from cancer or from the current social context.

Post traumatic stress could cause these cancer survivors to avoid health care because the environment is upsetting and health professionals want to talk with the adolescents about their cancer. “We can’t change the treatments they received in the past to save their lives, but we can do things to relieve their

psychological stress and to relieve post trauma symptoms that might be interfering with healthy behaviors or might be adding to their risk,” she said.

The researchers are studying childhood cancer survivors between 15 and 29 years old. In addition to having childhood cancer, the stressors for this age group include dealing with the bad economy, living through September 11 as a child, and struggling to afford school and find work.

Dr. Santacroce and her team examined three groups: adolescents with no exposure to a chronic illness, childhood cancer survivors, and the siblings of childhood cancer survivors.



Dr. Mayer is part of a team developing an e-health smart phone application that delivers physical activity interventions to newly-diagnosed colon cancer patients after their treatment ends.

E-HEALTH APPLICATIONS DELIVER CANCER INTERVENTIONS TO MORE PEOPLE

The sheer volume of cancer patients means that everyone may not have access to the best care and thus might not get interventions that could improve their lives. Associate Professor Dr. Deborah Mayer is leveraging technology to deliver interventions to newly-diagnosed patients and survivors of various types of cancer. “I like to use e-health applications to disseminate interventions in a way that works for the patients or to get those interventions to a larger audience,” she said. “A good application can reach a limitless number of cancer patients or survivors, allowing us to influence or improve their care.”

Dr. Mayer works with a team from the University of Wisconsin on the Comprehensive Health Enhancement System (CHES), an interactive e-health application for delivering interventions. The researchers are developing and testing a Web-based program, and they adapted it for use on a smart phone.

They are exploring how a phone delivered intervention would differ from one developed for a Web site. “We are testing the principle of the idea of whether we can create a program that would be of value, and then we are examining whether we can get people to use it on a phone,” Dr. Mayer said.

In one study the smart phone version of CHES is delivering tailored physical activity interventions to men and women with newly-diagnosed colon cancer when their treatment ends. Physical activity is important for this group because there is beginning evidence that a sedentary lifestyle contributes to the initial diagnosis of colon cancer and to an increased risk of recurrence after diagnosis.

Using a smart phone with the CHES application, users can see graphical displays of their physical activity, receive audio reminders to exercise and get positive reinforcement when they do. In addition, CHES provides information about colon cancer, monitoring for recurrence, and has a social support component that allows users to connect with others using the system.

The interventions delivered through CHES are aimed at helping users to develop:

- competence in information gathering, decision-making and behaviors they are trying to change
- social support systems to help them deal with the cancer experience
- autonomy from regaining a sense of control over their lives

The researchers will compare colon cancer survivors that use the mobile CHES system to those that get more traditional care to see if those in the CHES group have more physical activity, weight loss, less distress and a better quality of life. The study is now recruiting patients, and the researchers should have some answers to these questions in the next two to three years.



Kathryn Bauk, a master's student who is part of Dr. Santacroce's research team, examines the saliva samples used to measure the levels of stress hormones in childhood cancer survivors. Master's student Avanee Patel and Biobehavioral Laboratory Research Assistant Victoria Knick, MT (ASCP), are also pictured.

The researchers collected demographic, medical, psychological and biomarker data from the participants and took saliva samples to analyze cortisol and dehydroepiandrosterone (DHEA). The adrenal gland releases the hormone cortisol in response to stress, and in this study cortisol morning rise and diurnal slope were 2 of 14 potential indicators of risk for future heart disease.

Dr. Santacroce and her team were not sure that busy adolescents and young adults would even enroll in a study that involved venous puncture or would do what the study required regarding collecting saliva samples for analysis. They found that not only were adolescents from each of the three groups eager to participate but they were also highly adherent to the study requirements for saliva sample collection and reporting the exact time and level of stress for each sample by text to the study cell phone. The researchers are currently analyzing data from the study and plan to continue this work in larger studies.

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IMPROVING PROGNOSIS

Understanding how breast cancer reoccurs or spreads is an important question for Assistant Professor Dr. Theresa Swift-Scanlan. "We use the term breast cancer, but it is deceptive because in reality there are many different types of breast cancer that all behave differently," she said.

Research led by Dr. Charles Perou, an associate professor from UNC Healthcare's Lineberger Comprehensive Cancer Center, was instrumental in identifying breast cancer subtypes by examining gene expression. It is now known that some risk factors such as environmental exposures and estrogen exposure affect subtypes differently. For example, women who breastfed multiple children for longer duration have a decreased risk of the basal-like breast cancer subtype but not a decreased risk for the luminal A subtype.

Today, population-based statistics are used to guide a patient's treatment, to determine the risk of a tumor metastasizing, and to decide on what future screening is needed. For example, a patient may be told that a certain treatment is best because 30% of patients with the same kind of breast cancer have a reoccurrence. However, there has been no way to predict whether that patient would fall into the 30% or not.

To develop individualized information on breast cancer prognosis, Dr. Swift-Scanlan is studying epigenetic changes — changes in DNA that relate to its packaging in the cell rather than its primary sequence. She studies a specific epigenetic change known as DNA methylation in which a methyl group is added to DNA.

DNA methylation appears to be related to cancer and to occur early in the process of cells becoming cancerous. "For me, the potential promise is to identify methylated genes and use those as markers to improve prognosis," she said. "I want to determine if methylation of specific genes is associated with cancers that either reoccur or metastasize."

She is studying whether DNA methylation can be combined with information on breast cancer subtypes and environmental



Dr. Swift-Scanlan's research is aimed at finding epigenetic changes that could provide individualized information on whether a patient's breast cancer is likely to reoccur or metastasize.

Dr. Swift-Scanlan is still collecting data, but for some subtypes of cancer she is seeing patterns of DNA methylation that are specific to genes and/or cancer subtype. She plans to work with Dr. Perou and Dr. Robert Millikan, Barbara Sorenson Hulka Distinguished Professor in Cancer Epidemiology at the UNC Gillings School of Global Public Health, to validate the methylation markers she identifies. She will see if the differentially methylated genes she found with Perou correctly identify tumors by subtype or menopausal status in African-American women with breast cancer participating in the Carolina Breast Cancer Study. She will also be examining whether the methylated genes might predict which tumors are likely to recur or metastasize.

"In terms of recommendations and interventions we have a long way to go because we are still trying to understand a lot about the biology, but the data we have so far are encouraging," said Dr. Swift-Scanlan. ■

exposures in a way that may ultimately reduce mortality in African-American women with breast cancer. Even though breast cancer doesn't occur as often in African-American women, those that do develop it are more likely to have complications or to die from the disease. African-American women are also more likely to be diagnosed at an advanced stage, to be premenopausal at diagnosis, and to have aggressive breast cancer subtypes.

A CRUCIAL NEED: FUNDING TO ESTABLISH AN ONCOLOGY NURSING PROFESSORSHIP

Everyone is touched by cancer at some point in their lives — directly or through family, friends and others in their community. Nursing plays a critical role in the diagnosis, treatment, and management of the cancer, as well as in maximizing quality of life for those touched by it. And yet we are facing a workforce shortage in oncology nursing at a time when the number of people being diagnosed with cancer is growing and people are living longer with cancer and the after effects of cancer treatment.

Oncology nurse researchers are at the forefront of developing interventions that can help those dealing with this illness and their families from the time of diagnosis through survivorship or bereavement. Nurse researchers at UNC Chapel Hill SON recruit and mentor doctoral students to develop innovative approaches to cancer care. These researchers also teach nurse practitioner and nursing students about best practices for the care of people who are at risk for or affected by cancer. Nurse scientists make significant contributions to improve the quality of cancer care and the quality of life for people who have been touched by cancer locally, regionally, nationally and internationally.



A Distinguished Professorship in Oncology Nursing will recognize and support an exemplary nurse-faculty leader who is making a significant contribution to this field. An endowed professorship also provides distinction and recognition to the donor or a loved one. If you or someone you know wants to make a difference by promoting excellence in cancer nursing and in improving cancer care through education and research, consider creating an endowed professorship in Oncology Nursing. Please contact Norma Hawthorne at (919) 966-4619 or Norma_Hawthorne@unc.edu for more information.