

Eng, CCARES collaborate to tackle racial disparities in cancer care

When breast cancer patients believe that their disease is being adequately managed, they are likely to stick with a treatment plan, UNC Gillings School of Global Public Health researchers have found.

But the research project, led by Eugenia Eng, DrPH, UNC professor of health behavior and health education, also shows that when patients' questions about their treatment go unanswered, or their chemotherapy schedules are inflexible, or inadequate or inconsistent information is provided about follow-up care, then they are more likely to stop or delay treatment.

For patients, maneuvering through cancer treatment can be unnerving – or, as one patient described it at a recent health forum, it's like riding a bicycle down a road and trying to avoid the potholes.

Preliminary findings of the study show that a disproportionate number of the people who

stop or delay treatment are African-American women. A recurring concern expressed by women in the study was that they were unlikely to speak up about their needs or concerns if they had negative encounters with authority figures at critical points during their course of treatment. Instead, they would stop or delay the treatments.

Eng's study is a collaborative effort called CCARES (Cancer Care and Racial Equity Study), which has been underway for the past four years in Greensboro, N.C. CCARES uses a community-based participatory research approach to examine the different ways patients and caregivers communicate. The study also explores differences in how care



Dr. Eugenia (Geni) Eng addresses a public health forum in Greensboro, N.C., in June, reporting preliminary findings from the CCARES research.

is given and received within a local medical community. Breakdowns in communication can be caused by cultural differences, Eng explains, and can lead to racial disparities in treatment and care.

The study led researchers to conclude that the structure of a cancer care system actually can *promote* racial inequities. While this is not intentional, it can harm patients, and the longer the disparities exist, the more difficult it becomes to acknowledge the problem and change the system. The way to improve patient care, Eng said, lies in improving health care as a system, not just as a relationship between doctors and patients.



“I don't think they treat you like they should. I was getting too much chemotherapy until my doctor discovered the mistake, and then when I had radiation, they didn't tell me anything about wearing the (compression) sleeve to cut swelling. I hope this (study) will make things better for others in the future.”

– Shirley Weatherford, 72
Greensboro, N.C.



PHOTOS BY BONNIE STANLEY/BONNIE STANLEY PHOTOGRAPHY

Above, a patient at a health forum in Greensboro describes her difficulty navigating the health care system for her and her husband. At right, Brandolyn White, community outreach specialist with the Carolina Community Network, chats with CCARES project coordinator Christina Hardy (right) before the forum.

Improving care for African-American women is especially urgent, she says.

“What we are trying to understand is why there’s a racial disparity in breast cancer treatment – and we are focused on the system,” says Eng. “We’re not blaming doctors or nurses or care providers, but we’re trying to understand what it is about the system that produces these disparities.”

As part of the study, 50 breast cancer survivors were interviewed more than once about details of treatment that occurred five or six years earlier. Of these, 15 had delayed or discontinued their care.

The interviews used a qualitative research approach called “Critical Incident Technique,” first used by the U.S. Army Air Forces in World War II to improve pilot training programs by determining why missions were not completed as planned. In this study, the approach allows researchers to address all aspects of cancer treatment as a system,

rather than just as a relationship between patient and doctor.

The study, funded by the National Cancer Institute and Greensboro’s Moses Cone-Wesley Long Community Health Foundation, also found that doctors typically do not receive specific information about the progress of their patients’ treatment and may not know whether a patient has missed an appointment or decided to stop treatment.

Christina Hardy, MPH, project coordinator for CCARES in Greensboro, says one preliminary study recommendation is to better

that the system can track them better, and we hope that it can be a model for others.”

CCARES was formed by the Greensboro Health Disparities Collaborative, a joint initiative of The Partnership Project (a community organization committed to “undoing racism” in Guilford County, N.C.), the UNC Center for Health Promotion and Disease Prevention and the UNC Program on Ethnicity, Culture and Health Outcomes. Moses Cone Health System also joined the project, committing to work with local health care providers to help identify improvements in the care process.

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– UNC Professor Eugenia Eng

inform physicians about patients’ treatment progress and status.

“We are making suggestions for how health care institutions can be modified to better track cancer patients,” Hardy says. “Sometimes, women go in for chemo or radiation on a frequent schedule but they won’t see their oncologist again for six months. If a woman discontinues her care, how would the oncologist know? We are trying to find a way

Eng and colleagues are preparing a new grant proposal that will build on CCARES’ findings and expand research to include the Greensboro Health Disparities Collaborative and cancer centers affiliated with Moses Cone Health System, the University of Pittsburgh and East Carolina University. Using the collaborative experience, they hope to improve cancer care for all patients. ■

– By Kim Gazella