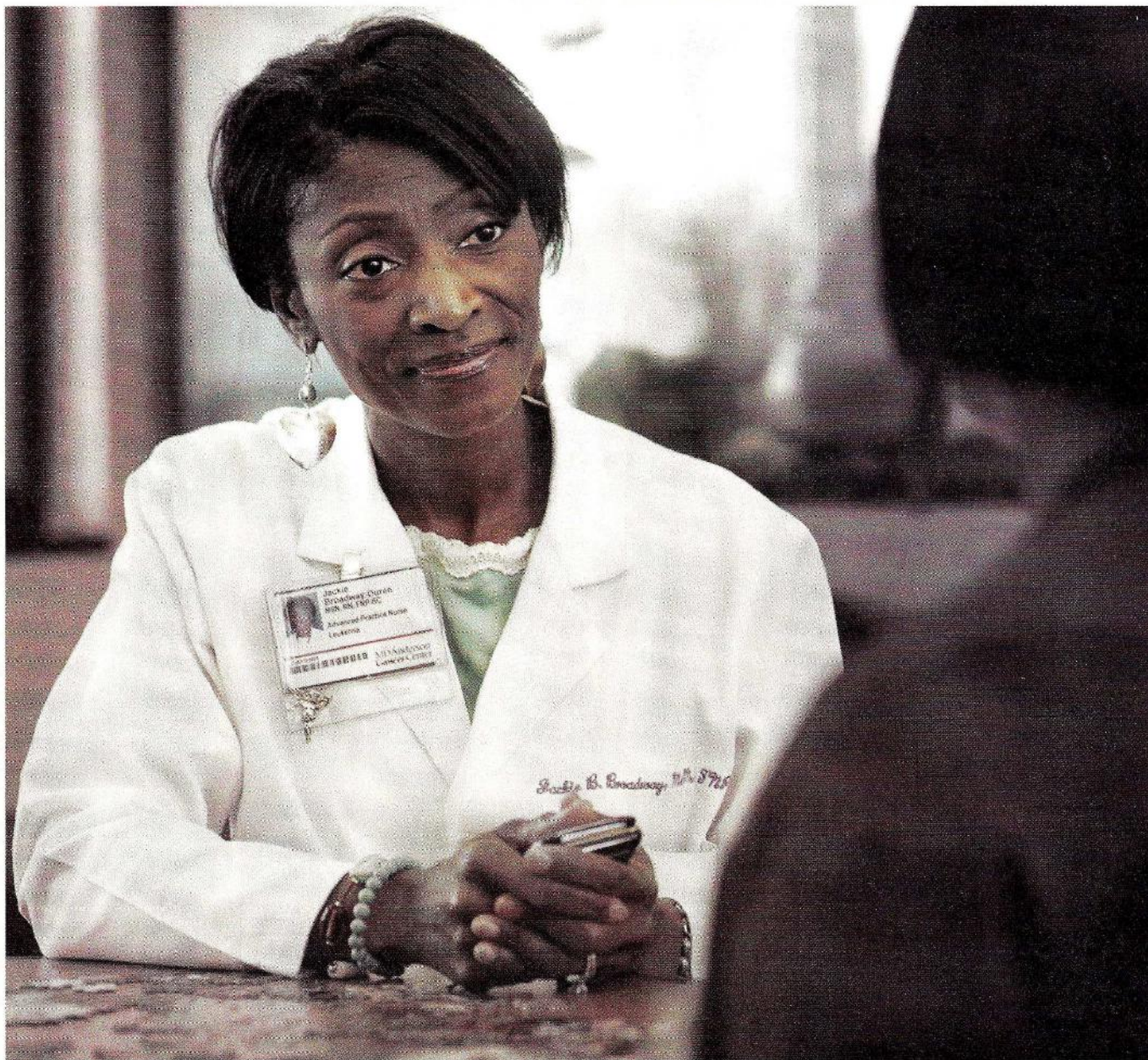


Jackie Broadway-Duren, MSN, RN, FNP-BC, says getting to know the family can make a difference in caregiver stress.



PHOTOS BY CHIP GILLESPIE

Double Duty

Help your patients by supporting their caregivers

By Stephanie Stephens

THE HUSBAND of a 38-year-old woman with terminal cancer said he was done. "I can't deal with this anymore," he confessed to Jackie Broadway-Duren, MSN, RN, FNP-BC. His wife's metastatic breast cancer had spread to multiple organs, and she was dying. His daughter had falling grades at college, and his 14-year-old son was acting out in negative ways. The patient's mother had stepped in as head of the family.

Broadway-Duren, an oncology nurse practitioner at M.D. Anderson Cancer Center in Houston, says the family was not made aware of the extent of the disease, and by the time they figured it out, they were devastated. She finally confronted the family, asking them to resolve their issues, so the patient could have peace.

One challenge for nurses is knowing when to intervene in family issues, Jackie Broadway-Duren says.



When the patient died, her family was at her bedside, Broadway-Duren says, but

there was tension between the husband and mother.

Research indicates that caregivers develop stress when their emotional or physical health is compromised or when the demands of care outweigh their available resources.

And the health of the caregiver is intrinsically connected with the health of the patient.

When caregivers feel more prepared and confident, patients receive better symptom management, have more energy, feel less ill and spend less time in bed. Caregivers, in turn, have less fatigue, strain and

ing research and education at City of Hope National Medical Center in Duarte,

Calif. She refers to prior City of Hope research on pain management, which reports that family caregivers' fear of addiction and pain tolerance for the patient were worse than the fear experienced by the patients themselves.

An oncology nurse for 34 years, Ferrell encourages nurses not only to understand what the caregiver experience is "really like," but also to identify early the caregiver's weaknesses and strengths. "Don't simply strive to provide the best care. Incorporate what you know about the family into the patient's care."

"The nurse
as a role model encourages open communication and sets the tone."

—LAUREL NORTHOUSE, PhD, RN, FAAN

depression. The challenge for nurses is identifying how caregivers are doing and when best to intervene, especially as cancer treatment is increasingly administered on an outpatient basis.

Dealing with Burnout

"Some caregivers burn out; some can't accept reality," says Broadway-Duren. "Some stay close by 24 hours a day and won't leave to get water or eat—too emotionally involved and needing to be in charge. When we spend more time getting to know these families, we have a chance to make a powerful impact."

Caregiver stress doesn't always manifest itself in emotional outbursts. Research has repeatedly shown that, if left unchecked, family caregiver strain can lead to poor health outcomes for caregivers.

"If you're focusing only on the patient, you're not really providing the best care," says Betty Ferrell, PhD, RN, FAAN, professor in the division of nurs-

Nurses often learn that families are overwhelmed and confused about what's really happening, Ferrell adds. "[When] they're in shock, they need support to make sense of all the issues," she says. "Then mobilize—get the social worker involved, refer to a chaplain or psychologist and to other community resources. You need everyone on the interdisciplinary team to help support family caregivers."

Laurel Northouse, PhD, RN, FAAN, professor at the University of Michigan School of Nursing and codirector of the Socio-Behavioral Program at the university's Comprehensive Cancer Center in Ann Arbor, says caregiving is its own full-time job, causing caregivers to struggle with their own roles and responsibilities while tending to those of someone else.

Caregivers may develop symptoms that mirror the patient's, Northouse says, including mental fatigue and difficulty with problem solving, organization and memory. Anxiety, depression, tension and irritability

[Professional Training]

THE FIVE-YEAR professional training projects include four national courses held in Anaheim, Calif., under the direction of Betty Ferrell, PhD, RN, FAAN. **The goal is to improve quality of life and of care for family caregivers impacted by a loved one's cancer through educating competitively chosen two-person multidisciplinary teams that develop goals to be followed at six, 12 and 18 months post-course.**

For more details, contact Project Director Jo Hanson at familycaregiver@coh.org.

For more information, visit cityofhope.org/education/health-professional-education, and click on **Programs for Health Professionals**.



can occur, along with physical fatigue and symptoms such as back pain and insomnia. A 2005 *Journal of Clinical Oncology* study noted 13 percent of caregivers for advanced cancer patients actually met criteria for a psychiatric disorder. Caregivers are also at risk for increased use of alcohol and other substances.

Finding the Right Interventions

"When stresses mount, a family caregiver can feel totally overwhelmed and helpless," says Ferrell, who is facilitating a National Cancer Institute grant-funded educational program for professionals on how to provide better support for caregivers.

When the caregiver is an elderly spouse, Ferrell says, stressors can quickly multiply. For example, an older caregiver "may have five to eight medical diagnoses of their own, such as hypertension, arthritis, cardiac disease or diabetes. In addition, they're probably not

sleeping or eating sufficiently and are neglecting their own healthcare needs." One study found that caregiving spouses aged 66 to 96 have a 63 percent higher risk of dying than noncaregivers in the same age group.

Northouse and Barbara Given, PhD, RN, FAAN, of Michigan State University College of Nursing, presented an educational session at the Oncology Nursing Society Annual Congress this year, "Cancer and the Family: Using Research to Improve Practice," which explored the effects of cancer on the family. Caregivers are "the bedrock of chronic care providers in the U.S., the primary source of support to people with cancer and first responders to changes in patients' conditions," they said, noting that 20 to 30 percent of families involved in caregiving are at risk for long-term problems. They recommend early intervention to alleviate persistent problems (see download, page 61.)

"The nurse as a role model encourages open communication and sets the tone," Northouse explains. Communication, as in any interpersonal dynamic, is essential to maintaining an open dialogue, not only between patients and healthcare providers, but also between patients and caregivers. For example, other studies show that spouses of advanced prostate cancer patients report a decrease in quality of life and greater levels of distress and uncertainty than their husbands.

Expecting the Best

Having recently lost her father to cancer, nurse practitioner Andrea DeAgostino, MS, RN, NP-C, of Ann Arbor, Mich., reflects that "if caregivers only knew in the beginning what they wind up learning by the end of it, the journey would be different. There is just no way to get that until you go through it. One of the most important things nurses do is to make patients and caregivers feel safe during their experience, to feel like they are being cared for."

"Maybe it's because sometimes we're so busy, [that] to ask opens a 'can of worms,'" DeAgostino says. "Still, caregivers need the validation that we get it, that they are going through this, too and that we support them. Making that connection means everything, even if it takes time from your schedule." **EH**