

for the family members and other volunteers who look after them.

In particular, Dilworth-Anderson and her team focus on the needs of those with limited access to health resources and those whose health literacy (or ability to obtain and understand basic health information and services) is limited. Many live in rural areas, which may result in further barriers to health care.

“Our research team works to understand the challenges of caring for older adults with dementia, the role of culture in shaping the caregiving experience, and what this provision of care actually means to caregivers and their families,” Dilworth-Anderson says. “Three of our recent studies have provided insight into how caregivers perceive dementia, their level of knowledge about the disease, and resources and services available to patients and caregivers.”

Dilworth-Anderson’s “Perceiving and Giving Meaning to Dementia” study surveyed 85 people from 25 racially and ethnically diverse North Carolina families to examine the influence of cultural values upon perceptions about demen-

tia caregiving and health care access. The study found that most caregivers mistook early signs of dementia for normal behavior. Coping also was determined to be a dynamic process, often handled differently according to culture.

In the “Cultural Meanings and Reasons for Dementia Caregiving” study, a telephone survey of 200 caregivers was intended

to uncover cultural and personal reasons why caregivers provide care to their older relatives. The study found that caregivers accepted their role because of family values and community expectations. They reported seeing themselves as being available, responsible and compassionate.

“Train the Trainer: A Dementia Care Project” is aimed not only at understanding

PHOTO BY LINDA KASTLEMAN



Dr. Peggys Dilworth-Anderson (center) poses with her research team (l-r), health policy and management graduate students Elise Lockamy, Diedre Boozer and Tandra Hilliard, and HPM alumna Allyson Banas.



Ten Warning Signs of Alzheimer’s

Memory changes that disrupt daily life

What’s typical?
Sometimes forgetting names or appointments, but remembering them later

Challenges in planning or solving problems

What’s typical?
Making occasional errors when balancing a checkbook

Difficulty completing familiar tasks at home, at work or at leisure

What’s typical?
Occasionally needing help to use settings on a microwave or record a television show

Confusion with time or place

What’s typical?
Getting confused about the day of the week but figuring it out later

Trouble understanding visual images and spatial relationships

What’s typical?
Vision changes related to cataracts

From the UNC Institute on Aging’s *Alzheimer’s Dementia Caregiver Resource Guide* (<http://tinyurl.com/UNC-caregivers-guide>)

caregiver dynamics but also at providing caregivers with information and education about dementia and normal aging and introducing available resources and strategies for self-care and stress management. Caregivers, who learned through the training how to recognize signs of dementia, are continuing to share the information within their respective communities.

Among their insights? “I need to try to stay positive – stay in good health so I will have strength and energy to be the caregiver I should be,” one person told Dilworth-Anderson. “I have to laugh more, and be more of the mindset to be in the moment with my mom,” another told her.

To date, 443 caregivers in North Carolina have participated in the project.

Dilworth-Anderson and her team currently are conducting town hall meetings to promote awareness and disseminate dementia care information to further empower rural and medically underserved communities in the state.

About 170,000 North Carolinians had been diagnosed with Alzheimer’s in 2010; by 2025, the number is expected to rise to 210,000. AARP estimates that there are 357,000 unpaid caregivers (family members and friends) for people with Alzheimer’s disease in our state.

Traditions and culture in North Carolina – especially in rural areas and small towns and

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among African-American families – influence people to care for their family members themselves, Dilworth-Anderson said.

“It’s kind of a tradition in our family,” one caregiver told her. “We take care of each other.”

Another explained, “She’s my mother, and I love her and respect her. She raised me, and now it’s my time to give back to her.”

Dilworth-Anderson says it is very rewarding to be able to help older adults and their caregivers cope better with the challenges of dementia.

She will continue to conduct this type of work, she says, “because as a scientist, I know that research findings, when translated, disseminated and applied well, can have a positive influence on older people with dementia, their family caregivers and friends who help care for them.”

Caregiver guides from the project are available on the website of the UNC Institute on Aging (www.aging.unc.edu).

Dilworth-Anderson, past president of the Gerontological Society of America and recipient of the Ronald & Nancy Reagan Research Award in Alzheimer’s Research, has received support from the Alzheimer’s Association, GlaxoSmithKline Community Partnership Program, Agency for Health Care Research and Quality, and the National Institute on Aging.

– **Ramona DuBose, Linda Kastleman and Angela Spivey** contributed to this article.

(as compared to “What’s typical?” for normal age-related changes)

New problems with words in speaking or writing

What’s typical?
Sometimes having trouble finding the right word

Misplacing things and losing the ability to retrace steps

What’s typical?
Misplacing things from time to time, such as a pair of glasses or the remote control

Decreased or poor judgment

What’s typical?
Making a bad decision now and then

Withdrawal from work or social activities

What’s typical?
Sometimes feeling weary of work, family and social obligations

Changes in mood and personality

What’s typical?
Developing very specific ways of doing things and becoming irritable when a routine is disrupted



Read more at www.aging.unc.edu or www.alz.org.