BOUSTANI: 'We constantly learn. There is no wall between research and operations.'

3 Robust Approaches to DEMENTIA CARE

BY GERI ASTON

A weird combination of health care and engineering is how Malaz Boustani, M.D., founding director of the Sandra Eskenazi Center for Brain Care Innovation, describes the Aging Brain Care program at Eskenazi Health in Indianapolis.

That's because the program staff is engaged in implementation science and is focused on developing, testing and deploying not just new types of care, but also new ways of delivering care to its population of patients with dementia, Boustani explains.

"We constantly learn," he says. "There is no wall between research and operations."

That theme is clear in the program's evolution. It started in 2008 with the Healthy Aging Brain Center, an outpatient memory care clinic. Today the center is still active, but most services are delivered by care coordinator assistants without patients leaving their homes.

The program focuses on the patient and his or her caregiver. Services don't just address medical issues, but behavioral and social issues, as well. Boustani calls it biopsychosocial care.

The incidence of dementia is rising as the senior population in the U.S. grows, and Eskenazi Health is not alone in its efforts to develop new, efficient ways to care for those afflicted. An estimated 5.4 million Americans have Alzheimer's disease — a figure projected to climb to 14 million by 2050. That doesn't include people with other forms of dementia.

Dementia care medical home

At the Healthy Aging Brain Center, care begins with a full workup to determine which form of dementia the individual has and its stage. An assessment is made of the patient's and caregiver's needs, including nonmedical needs.

Together with the patient, the caregiver and the patient's primary care physician, the brain care team develops an individualized care plan. It has two parts — one for the patient and one for the caregiver. Ninety to 95 percent of care plan implementation is handled by the brain care team, and the rest by the primary care doctor, Boustani says.

The patient is taken off any medication that could worsen dementia and given medication that is more effective for the dementia and for any chronic conditions that could complicate it. The team works with the primary care physician to simplify the patient's overall drug regimen to make adherence easier. Patients who have the cognitive capacity receive education on their disease and help with advance care planning.

Photograph courtesy of Eskenazi Health

Caregivers, who are typically spouses, offspring or other family members, are educated about dementia and coached on problem-solving strategies. They are advised to take a weekly eight-hour rest from caregiving and to participate regularly in a support group. The center team also helps them to develop a crisis plan to deal with problems that inevitably arise and such difficult issues as deciding when their loved ones should no longer drive, when a hospital or emergency department visit is appropriate, and how to decide when it's no longer safe for their loved ones to stay at home, Boustani says.

Care coordinator assistants provide most follow-up services using Eskenazi's Aging Brain Care Medical Home model, which started as a small pilot program in December 2009. In 2012, the project earned the medical home a $7.8 million health care innovation award from the Centers for Medicare & Medicaid Services that enabled it to expand from a few hundred patients to 1,500.

The assistants, who must have at least a high school diploma, are supervised by registered nurse care coordinators who work with social workers. The program has 10 assistants, with the capacity to employ 15, three RNs, and three social workers, all of whom are supervised by four doctors who share one full-time position.

Before care coordinator assistants are hired, they're screened for important personality traits, including feeling comfortable going into patients' homes and working with elderly people, the ability to deal with constant change and to work as part of a team. They undergo training, which includes simulations of situations they might encounter.

> Dementia care programs interate services in the hospital and out, and among clinical and family caregivers.

The assistants regularly monitor patients with a questionnaire tool that assesses dementia symptoms in four categories: cognitive, functional, behavioral and mood. It also measures caregiver stress. "We call it a blood pressure cuff for dementia," Boustani says.

Based on the results, patients are put into zones ranging from green for those doing well to red for those faring poorly. The team meets weekly to discuss patient care, resolve issues with the patient or caregiver, and revise the plan if necessary.

The assistants, equipped with cellphones and laptops, visit patients at least one a month for the first three months and at least every three months thereafter. Their mobility allows them to meet patients in their homes, doctors' offices, the hospital or in the community.

The brain care team's work is supported by software called eMR-ABC, developed for the program by Indiana University and the Regenstrief Institute, a health-focused research organization in Indianapolis. Using data generated from the patient assessments, the tool offers individualized decision support.

The electronic health record tool is integrated with the Indiana Health Information Exchange. The brain care program receives an alert when one of its patients is hospitalized or visits an emergency department anywhere in Indiana.

That alert prompts the brain care staff to contact the hospital team to provide information on the patient's health and social support and to offer aid with patient care and discharge planning. One of the brain care nurses visits the patient within 72 hours of discharge to conduct medication reconciliation and make sure discharge instructions are followed.

Hospitalizations and ED visits are signals of a breakdown in care coordination, Boustani says. Both are extremely disruptive for patients with dementia and their caregivers and raise the risk of complications common for dementia patients. The goal of the regular patient and caregiver assessments and home visits is to prevent problems that could cause hospitalization or a trip to the ED. "If you don't fall, then you don't need to go to the hospital," Boustani explains.

The hope is that care coordination will improve patient care and, in the process, prevent costly problems. An April 2014 study in the journal *Health Affairs* found that the Healthy Aging Brain Center generated a net savings of $2,856 per patient per year, split almost evenly between reduced inpatient medical expenditures and decreased ED and related expenditures. Boustani cautions that while the data on brain care medi-

Most common forms of DEMENTIA

Dementia is a descriptive term for a collection of symptoms that can be caused by a number of disorders that affect the brain. Here are some of the most common forms of the disorder.

ALZHEIMER'S DISEASE

INCIDENCE: Alzheimer's is the most common from of dementia, affecting an estimated 5.4 million Americans. It's the sixth-leading cause of death in the U.S.

DESCRIPTION: Alzheimer's is a fatal, progressive brain disorder that damages and eventually destroys brain cells. Its hallmarks in the brain are plaques of a protein fragment called beta amyloid, twisted microscopic strands of the tau protein, and loss of the connections that transmit information between cells.

SYMPTOMS: Early signs include difficulty remembering recent conversations, names or events; apathy; and depression. Later symptoms include impaired communication, poor judgment, disorientation, confusion, behavior changes, and difficulty speaking, swallowing and walking.

VASCULAR DEMENTIA

INCIDENCE: This condition is the second most common cause of dementia. It accounts for about 10 percent of dementia cases.

DESCRIPTION: Vascular dementia is caused by damage from strokes. The location, number and size of the brain injury determines the effect on thinking and physical functioning.

SYMPTOMS: Impaired judgment and ability to make decisions, and impaired planning or organizing skills are likely the initial symptoms, as opposed to the memory loss associated with Alzheimer's.

DEMENTIA WITH LEWY BODIES

INCIDENCE: This is thought to be the third most common cause of dementia. It accounts for 10 to 25 percent of cases.

DESCRIPTION: Abnormal aggregates of protein that develop inside nerve cells, called Lewy bodies, build up in the brain. Lewy bodies are also found in other brain disorders, including Alzheimer's and Parkinson's disease dementia.

SYMPTOMS: The condition may cause changes in alertness and attention, hallucinations, problems with movement and posture, muscle stiffness and confusion. It's hard to diagnose because Parkinson's and Alzheimer's cause similar symptoms.

PARKINSON'S DISEASE DEMENTIA

INCIDENCE: An estimated 1 million Americans have Parkinson's disease, and 50 to 80 percent of them eventually experience Parkinson's disease dementia.

DESCRIPTION: Parkinson's is a chronic, progressive movement disorder that involves the malfunction and death of neurons in the brain. As damage spreads, dementia may arise.

SYMPTOMS: Parkinson's disease dementia is marked by a decline in memory, thinking and reasoning. The average time from onset of Parkinson's to developing dementia is about 10 years.

Sources: Alzheimer's Association and the Dementia Society of America cal home savings are promising, more is needed.

Teamwork treatment model

In Los Angeles, a $3.2 million, three-year CMS health care innovation award enabled UCLA Health to launch its Alzheimer's and Dementia Care Program. It considers the person with dementia and the caregiver as a dyad. "Ultimately the patient's health and well-being are inexplicably tied to the caregiver," says Zaldy S. Tan, M.D., a geriatrician and the program's medical director.

The care team includes Tan and five nurse practitioner dementia care managers. Dementia care managers begin work on each case before the initial visit by gleaning information from the patient's EHR on his or her type of dementia and any comorbidities.

The patient or caregiver completes a previsit questionnaire that deals with medical issues and aims to identify any social problems the patient and caregiver might face. It asks where they live and whether they have access to community-based resources, belong to a support group, have financial concerns or have difficulty getting medications.

The dementia care manager conducts an initial 90-minute visit that is an opportunity to get to know the patient and caregiver. Both are assessed for depression and the caregiver is additionally assessed for the ability to advocate for his or her own needs.

The care manager drafts a personalized care plan, which is sent to the referring physician for approval. The care manager and the referring doctor, typically a primary care physician, co-manage the plan's implementation. The physician handles the medical aspects of the plan, including signing off on any dementia medicines the patient might need or other drugs to treat dementia-related problems.

"There is an ongoing discussion from that time on regarding that patient," Tan says. "With any hospitalization, ER visit or crisis, the dementia care managers try to take care of it as much as possible, but keep the physician in the loop."

The care coordinators handle patient and caregiver social needs and connect them to community services. UCLA offers several support groups and ongoing education on many dementia topics.

Patients and caregivers have year-round, 24/7 telephone access to dementia care advice and guidance, with on-call geriatricians covering for the care managers after hours. Caregivers typically use this service when a problem arises — for example, when the patient's behavior changes, the daytime sitter quits or the caregiver needs help with stress.

Many calls involve the patient's medical state. "Dementia is not static," Tan says. "That's why the relationship between the care manager and the primary physician is very important. The care manager might be the first one to be informed about a brewing illness. We try to intervene as early as possible by facilitating access to the primary physician whenever possible."

The dementia care team receives an alert when a patient is hospitalized or visits an ED in the UCLA system or another hospital using the same EHR. If the hospital is within UCLA, the care manager contacts the hospital team and offers assistance. If the hospital is outside the system, the care manager relies on the caregiver as a link to the hospital team.

"The important thing is the follow-up and the transition to make sure that when the patient is discharged, they're eased back into the community or the skilled nursing facility," Tan says.

When UCLA's program started, its leaders developed a registry of health system patients with dementia by running a search for dementia-related ICD-9 codes. "What we found was that a lot of people who, for example, are on dementia medications didn't have that dementia diagnosis in their problem list," Tan says. "A lot of their primary doctors … code for something else they're seeing the patient for, like hypertension or heart disease."

Program leaders went practice to practice explaining the program and how it could help doctors and their patients. As of July 2016, the program had served more than 1,800 patients and their caregivers. It has 1,200 active patients and a waiting list of 150, Tan says.

The five dementia care managers, two of whom speak Spanish, each have a 250-patient caseload — the maximum the program allows. Easing the wait list would require the hiring of another care manager, something Tan says he hopes to do in the future.

CMS estimated that the program would save $6.9 million over the grant's three-year period. The government hired an independent entity to compare the trajectory of health care cost for the dementia care patients with a control group, says Tan. The results aren't yet publicly available.

Federal funding has ended, and the program now is supported mostly by philanthropy, with some assistance from the health system, Tan says. The face-to-face visit with the dementia care manager is covered by insurance. "But

Caring for the caregivers at UCLA

Staff tracked the well-being of caregivers as they entered UCLA's Alzheimer's and Dementia Care Program. Here is what they found:

Before entering UCLA's Alzheimer's and Dementia Care Program, many caregivers were poorly informed and felt they were fighting this battle alone.

- 33 percent of caregivers had high stress and 13 percent were depressed.
- 62 percent said they didn't know where to turn for answers.
- 76 percent said they had no health care professional to help with dementia issues.

After entering the program, 94 percent of caregivers said they felt that their role was supported. By the end of a year:

- Confidence in handling problems and complications of Alzheimer's disease and dementia improved by 72 percent.
- Strain was reduced by 12 percent.
- Depressive symptoms and distress were reduced by 24 percent and 23 percent, respectively.

Source: UCLA Health, August 2016

there are lots of phone calls and messages and care coordination, like reaching out to the inpatient team or to the ER or participating in family meetings," he says. "Things like that that are currently not reimbursable."

Creating community connections

In St. Louis, much of the outpatient dementia care for Barnes-Jewish Hospital patients is provided at the Washington University School of Medicine's Memory Diagnostic Center by an advanced practice nurse and 10 physicians, mostly neurologists.

Diagnosis is made by reviewing the patient history, giving a complete physical and neurological exam, and assessing memory skills. Practitioners review previous medical test results, including CT and MRI scans of the head. The diagnostic summary, containing the diagnosis, treatment plan and follow-up care is sent to the referring physicians for approval.

Because the center's physicians also are involved in teaching and research, they typically see patients once every six months or once a year, says Joy Snider, M.D., neurology professor and Barnes-Jewish neurologist. However, the nurse practitioner, Cassandra Ward, sees patients more often and helps to coordinate care and provides dementia education. A full-time nurse provides phone support for patients and caregivers with questions or concerns.

Some patients are referred to the clinic because dementia is identified during a hospital stay. "We don't want to miss folks with an early dementia," Snider says. "If they get confused in the hospital, the neurology consult service will see them." If dementia is suspected, the neurologist refers them to the Memory Diagnostic Center.

In addition, any patient who receives an occupational therapy referral automatically receives a cognitive screening, says Stephanie Stegman, rehabilitation lead occupational therapist at Barnes-Jewish Hospital. Patients with such conditions as stroke, acute myocardial infarction and congestive heart failure, which carry a high risk of related dementia, automatically receive a full cognitive assessment.

Patients with these conditions also have a high risk of readmission, so Barnes-Jewish staff evaluate them for the Stay Healthy Outpatient Program. In it, a patient navigator nurse identifies whether they are able to see their respective primary care physiciasn within three to five days of discharge. If not, they visit an NP at the hospital's Stay Healthy Clinic. Clinic patients who show signs of dementia are connected to Ward, the Memory Diagnostic Center's NP.

For nonmedical services, the center and hospital staff often refer patients and their caregivers to community resources, including the St. Louis Area Agency on Aging, the St. Louis Chapter of the Alzheimer's Association, and Memory Care Home Solutions, a nonprofit organization that offers free in-home assessments and personalized caregiver training. "We've got great organizations in our city that really have partnered with us to the benefit of our patients," Snider says.

Although patients connected with the Memory Diagnostic Center after hospital discharge are seen right away by Ward, the Memory Diagnostic Center's typical wait time for patients referred by their doctors is six months.

To help patients who live outside the St. Louis metro area, Barnes-Jewish social workers and case managers have compiled a list of community neurologists who are accepting new patients, says Mary Spencer, R.N., executive director of the neuroscience, orthopedics and neuro-oncology program at the Siteman Cancer Center, operated by Barnes-Jewish Hospital and Washington University School of Medicine. "If there is someone who is taking memory and aging patients or Alzheimer's and dementia patients into their practices, we give the patient a referral as they leave so they can follow up with this physician closer to home."

In addition, the Washington University School of Medicine is working to bring dementia care access closer to patients through the Clinician Partners Program, offered by its Knight Alzheimer's Disease Research Center. The program offers a 2.5-day, all-expenses-paid mini-residency on the most current dementia diagnostic and treatment techniques for rural physicians, physician assistants and advanced practice nurses.

The country will need more specialists in dementia care in the future, Snider says. "That's something we're working on — doing better training for our residents, trying to get more medical students interested in geriatrics and neurology because it's a burgeoning population," she says. "There is just a desperate need for more general neurologists and geriatricians." — *Geri Aston is a contributing writer to* H&HN. ●

EXECUTIVE CORNER

The clinical and administrative staff involved in the Aging Brain Care project at Eskenazi Health offer several lessons learned in the 2015 book *Geriatrics Models of Care: Bringing 'Best Practice' to an Aging America.*

Relationship building: Stories from the care coordinator assistants who monitor and assist patients with dementia and their caregivers highlight the need to build the trust necessary to engage patients and caregivers in open, honest conversations about care.

Leadership backing: The enthusiastic support of the hospital system's leaders was an important first step in engaging primary care providers in the project.

Patient motivation: Patient engagement can be challenging. Staff members had to develop innovative ways to contact patients and caregivers, and they worked hard on the method and style of introducing themselves and explaining services.

Progress measurement: The project's electronic health record software allows staff members to continuously monitor outcomes so staff can make timely adjustments to individual care plans.

Feedback essentials: The program's consumer advisory board convenes every six months to give feedback and suggestions to improve the patient and caregiver experience. It has helped to identify patients' and caregivers' unmet needs and outcomes of interest. ●