Managing Mental Health: The Demands of Dementia

If Dr Malaz Boustani were tasked with grading dementia care he'd dole out an "F" for the United States. For him, the battle to improve upon this failing report card is personal. "My father and mother-in-law have suffered from dementia and are still suffering," he said, "and my wife is at a high risk."

Part of the cause for frustration is that not much has changed over the course of the last two to three decades, pointed out the chief innovation and implementation officer for the Sandra Eskenazi Center for Brain Care Innovation and professor of medicine at the Indiana University Center for Aging Research.

The prevalence of people with dementia is still on the rise due to an aging population and failure to prevent this syndrome, he said, and the current health care system recognizes less than 50% of patients living with dementia. For those who are actually treated, he said, the quality of care is miserable.

Some of the lack of large-scale change and improvement in recent decades, according to Dr Boustani, can be attributed to the slow recognition on the part of managed care organizations that dementia was impacting the quality of care of other chronic conditions as well as the bottom line. "They did not stratify their beneficiary to see why certain people are high utilizers and why certain people are not high utilizers based on dementia," he said. "They focused specifically on 'below the neck' chronic conditions—heart failure, COPD, and diabetes."

After realizing a problem does exist within the last 5 years or so, the methods implemented by managed care to resolve the issue haven't been all that successful, Dr Boustani said. To deal with unrecognized dementia, for example, primary care doctors were told to improve recognition, which only

added additional tasks to an already full plate. In addition, efforts tended to revolve around education rather than care coordination. “They thought the problem was knowledge,” he said, “and not implementation.”

Innovative Programming

As a geriatrician and implementation neuroscientist, Dr Boustani focuses on the rapid translation of research discoveries into clinical practice. He and his team have determined that the manner in which dementia care is delivered needs to be transformed, so they set to work on designing, testing, evaluating, implementing, and disseminating a new system called the Indiana University Aging Brain Care (IU ABC) model.

ABC is a collaborative dementia care model that targets primary care settings in particular, combining a care coordination team with software that constantly tracks performance and provides specific protocols and assessment measures. “We converted the clinical trial protocol into an actual clinical service,” Dr Boustani explained, “and we were able to accomplish the Triple Aim of better brain care at a lower cost.”

The manner in which he and his team of implementation scientists measure success, which he said is not just dictated by the number of grants received or the number of studies published, has helped contribute to the success of the program. “We measure our success by the number of lives we change,” he said. “We do discovery to delivery—not discovery to bookshelf.”

As the UCLA Alzheimer’s and Dementia Care Program was first being initiated, Program Director Dr David Reuben said he shopped around to see what was going on throughout the country. It was this program in Indianapolis that really caught his eye, so he initiated conversations in order to learn how to adapt and further develop the ABC model.

“We call it the co-management model,” he said, “which means that our Dementia Care Managers, who are nurse practitioners—there are 5 of them

now —manage the dementia aspect or the Alzheimer's aspect of the patient and work with the primary care physician."

Treatment begins with a 90-minute in-person visit with a Dementia Care Manager in order to determine the patient's needs and develop a personalized care plan, which is ultimately sent on to the primary care physician for approval.

"Think of it this way," Dr Reuben said. "We sort of adopt these patients. The treatment really is not just the patient. It is the dyad of the patient and the caregiver, and we firmly believe that the most important resource for patients who have Alzheimer's or other forms of dementia is not the doctors or the dementia care program; it's the caregivers."

The program partners with community-based organizations, and the payment structure means money actually flows out of UCLA and into the community to try to support these dementia services, he added.

Financial Burden Revealed

According to Dr Reuben, there's no reason why any managed care program couldn't adopt a similar model. "Managed care organizations are able to do this because they have great flexibility in how they spend their funds," he said. The bigger nut to crack, he added, is fee-for-service. And because there is no Medicare coverage for this right now, it's a big nut to crack.

It's a dilemma highlighted by a recent study published in the *Annals of Internal Medicine* that took a closer look at the social costs and financial risks faced by Medicare beneficiaries over their last 5 years of life.

It found that between 2005 and 2010, the average total cost of care in the 5 years prior to death for older Americans suffering from dementia was $287,038—significantly more than those who died from heart disease ($175,136), cancer ($173,383), or other causes ($197,286). Although

Medicare expenditures were similar across groups, the differences in average out-of-pocket spending were substantial. For dementia ($61,522), the expenditures were 81% higher than that for patients without the disease ($34,068).

“I think what a lot of people don’t realize is that health insurance—and Medicare in particular—just simply doesn’t cover the type of care that people with dementia need,” said lead author Amy S. Kelley, MD, an associate professor in the Brookdale Department of Geriatrics and Palliative Medicine at the Icahn School of Medicine at Mount Sinai.

“Medicare provides excellent coverage for hospital stays, surgeries, and doctor’s visits, but that’s not what people with dementia need to have,” she added. “They need to have someone with them to make sure they are safe. They need to have someone with them to make sure they can get out of bed or to make their meals. And that moment-to-moment, day-by-day care isn’t covered by Medicare at all.”

Because health care spending among those with dementia was substantially greater than those for other diseases and many of the expenses were uncovered, the study concluded, this places a hefty financial burden on families, particularly among subgroups of older adults who are at a greater financial risk. African Americans, the unmarried, and those with lower educational attainment all had a disproportionate amount of their household wealth consumed by these health-related costs.

Future Possibilities

On the one hand, Dr Kelley believes there is a great deal of hope for finding ways to delay the progression of dementia or even prevent it in the first place —what she refers to as the holy grails of dementia research. In the meantime, however, the medical community is dealing with the aging Baby Boomer generation, many of whom will suffer from dementia. “We need to figure out these solutions so that we don’t impoverish the whole country and all these

people's families in the meantime," she said.

One cost-savings measure that could be examined by health care providers and insurers is the difference between caring for an individual within a nursing home versus the community. In many markets, nursing home care is far more expensive than the cost of a caregiver within a person's home, Dr Kelley pointed out, and most older adults would prefer to remain in their own homes, if possible. It's an opportunity to provide the type of care desired while taking advantage of cost savings.

In addition, she wonders whether the spending patterns revealed by her study could be amenable to policy intervention that somehow provides different benefits or layers of support in order to reduce the financial burden taken on by families. As a society, she added, we need to consider whether we are doing our best to serve our oldest adults and protect the next generation of family.

Looking ahead, Dr Boustani said his program's goal is to spread the IU ABC model as quickly as possible in order to help meet the needs of those currently suffering from dementia. To help bring the model to market and spread the solution beyond Indianapolis, he and his teammates have turned to a local startup company (that he has equity in) called Preferred Population Health Management.

Similarly, one of the next phases of work at the UCLA Alzheimer's and Dementia Care Program will be to develop replication materials. The program is more effective and a lot less expensive than using drugs, said Dr Reuben, but it's not currently covered by health insurance. The ultimate goal for disseminating their model is to encourage the program to become a covered Medicare benefit.

Meanwhile, he emphasized that managed care organizations have the ability to implement this type of dementia care programming. "They have the statutory authority and the payment structure to be able to do something like

this now, and about a third of Medicare beneficiaries are in managed care," Dr Reuben said. "So the real question is, why not?"