‘Village of the Demented’ Draws Praise as New Care Model

BY DAN HURLEY

ARTICLE IN BRIEF
Featured is a novel model of care for demented patients, in which they live in a “make-believe” village that accommodates their interests and values.

N
o, it’s not a new cable series on AMC. Rather, Hogewey is a gated community founded two decades ago in a suburb of Amsterdam that has lately drawn imitators, praise, and press coverage as the world’s first “dementia village,” a radical rethinking of how best to care for people in the advanced stages of Alzheimer disease and other neurodegenerative disorders.

Most importantly, it’s definitely not a nursing home.

“It’s so different from a traditional nursing home, you can’t compare it,” Hogewey’s founding director, Jannette Spiering, told Neurology Today during an interview via Skype.

The village’s 152 residents live in a land of make-believe, in which small group homes are designed to look old-fashioned, caregivers dress casually, and residents are free to roam about to shop for groceries, fix a meal in a communal kitchen, have a beer at a bar, or walk the carefully tended grounds.

All this, at a publicly funded institution that has the same budget as other nursing homes in Holland, and the same population. In fact, with a long waiting list of families hoping to place their loved ones there, Hogewey accepts only those with severe dementia. Care is provided around the clock, with a staff-to-resident ratio of four caregivers to every patient. As at a traditional nursing home, physicians are always on standby.

Although 70 percent of Hogewey’s residents are ambulatory, those who are bedridden are included in all the daily activities, she said. “If you can’t walk, and you have to lie in a special chair, you are still part of a household and are still able to smell and hear and see.”

SHOWN HERE AT HOGEWEY, residents have a glass of wine at a bar. The village is designed to make residents feel comfortable in home-like settings.

LIFESTYLE GROUPINGS
Rather than grouping patients by medical criteria, each home of seven residents is designed to suit one of seven different lifestyles: urban, for those who lived in a city and like to walk about, domestic, for those who stay mostly indoors; cultural, for those who are interested in the arts and like to try new things; Christian, for those who deeply value church life, craft, for working-class people who prided themselves on their jobs; Indonesian, for those who most value their ethnic heritage; and one for upper-class people raised on proper manners.

Whereas the working-class residents have a friendly, casual relationship with caregivers, preparing meals together and perhaps eating while watching television, the upper-class residents sit more formally, with fine tablecloths and glasses, and meals are brought to them by caregivers who play the role of servants. Indonesians eat cuisine prepared in their native style, and have homes decorated in a native style, and have homes decorated in Indonesian style.

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Memory

PhD, said “such a study could provide insights into the subtle interaction in cognition that occurs between representations of the physical world and our internal thoughts.”

“This is the closest to an experience that a mouse might have when imagining that it is somewhere other than where it is,” they said.

In a telephone interview, Dr. Morris said the investigators paved the way for scientists to tap into internal memories to understand very basic and complex mechanisms that drive memory. He added that this technique may provide a way to explore the impact of memories on the laying down of new experiences in humans.

The advantage of such a technique, he said, is that scientists can now genetically activate specific spatial patterns of neurons. “We can ask fundamental questions about neural representations in recalling memories that we just could not do before now.”

(Dr. Morris’s early work in developing the water maze led to the understanding of many aspects of memory and spatial orientation. His group also discovered NMDA’s role in learning and memory and set the stage for a generation of studies with genetically engineered mouse models to explore memory.)

“There is so much we don’t know and this study shows that we can engineer a memory and later try to express it,” Dr. Morris said. “Can a mouse imagine? Well, not the William Blake kind of imagination, but we now know that animals can be in one place and imagine they are partly there and partly someplace else.”

“In my mind, this takes us an additional step closer to understanding the mind of a mouse. So far, it doesn’t tell us about human memory. If we imagine activation of a memory as a subset of cells firing, they re-created the firing of that subset in a different place. It is very clever.”

Still, scientists have a long way to go. Ultimately, they need a tool that allows them to record from thousands of cells at the same time. The Morris lab is now taking on the question of how the brain responds to a traumatic memory — a 9/11 experience, for instance — and why memories of trivial things that happen around that event take hold and last forever but may change over time as well.

Are animal models predictive of human behavior? No one is really certain that they are and that “is why we need to develop paradigms that could have more relevance to humans,” he said. “Animal work is not in a world of its own but is somehow related to how we think.”

Dr. Tyler said the approach is “incredibly clever.” The good news, he added, “is that you get the same neurons — the spatial context — but the bad news is that you can’t recreate any temporal context or sequential pattern of activation. The drug turns them on all together at same time.”

Still, “this alone is a pretty cool advance. Other methods of stimulating neurons, like electrical stimulation, would get all the neurons in a particular area. This singles out only those activated in the original context.”

REFERENCE:
with traditional art, including sculptures of Buddha. The “urban” homes, on the other hand, are decorated with a modern, uncluttered look. “We try to make it as much like your old life as possible,” Spiering said. “How you lived as a younger person is much more important than how you function now. It must be familiar. We create a surrounding and a way of living that they recognize and feel comfortable and anxiety is most often treated with medication. What they don’t do real- ize is how the setting itself can create anxiety. We build homes which look like normal homes, with a normal village-like surrounding, where you can meet your neighbors, where you go out shopping, where you cook your meals in your house, just like you used to do in your own house. We support people with dementia in doing this, because they can’t do this by themselves any more. We create a surrounding they recognize. Medication is lower, because people don’t feel trapped.”

A variety of studies published over the past ten years have documented clinical benefits in dementia patients placed in home-like settings with innovative layouts specially designed to encourage walking and engagement with daily activities.

“People with dementia do often get anxious and restless,” Spiering said. “In typical nursing homes, this restlessness

CLINICIANS WEIGH IN

Clinicians here in the United States expressed praise and curiosity about the approach, while raising the predictable questions and caveats about exactly how such a model could be translated.

“I would say it sounds very positive, if it works,” said Rachelle S. Doody, MD, PhD, the Effie Marie Cain Chair in Alzheimer’s Disease Research at Northwestern University in Chicago, said she had seen nothing like Hogewey in the United States. But, she added, “there is more and more effort in residential care facilities to make them more like a home and less like an institution. Other options are increasingly available for individuals with dementia. Physicians, including neurologists, should be aware of all the resources to help people with dementia find some meaningful activity in their daily lives in and outside of nursing home placement.”

FOCUS ON ENVIRONMENT FOR CARE

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“Environment makes an especially big difference,” said Habib Chaudhury, PhD, who studies architectural design for people with dementia as an associate professor at Simon Fraser University in Vancouver. “We talk about the importance of having a safe wandering path. Reaching a dead-end, a blank wall or a locked door is very frustrating and confusing for them. They need options for going places, to sitting areas, activity corners, things that attract them to engage.”

“I’m all for this,” he said. “I’m really excited about the second project being planned for Switzerland as well. These villages have the potential to simulate the daily life of people from when they were younger through various activities in the home and neighborhood. Villages can provide a much wider range of movement compared to a typical dementia care unit. It would be important to see if such a neighborhood environment has any beneficial effect in behavior, functional ability, and cognition.”

REFERENCES:


ETHICAL CONCERNS?

No ethical concerns regarding Hogewey’s make-believe approach were seen by Steven DeKosky, MD, professor of neurology and dean of the University of Virginia School of Medicine.

“I think personally there is nothing wrong with a system which in some ways is not exactly reality,” he said in an e-mail. After all, he noted, “persons who have significant cognitive impairment do not perceive the same reality as others. So my view is that if the family can be comfortable with an environment like this, where it is truly patient-centered, then it will work well.”

Despite the aspects of fantasy, Spiering said, there is nothing make-believe about her residents’ sense of freedom and calm.

“Today was a lovely day, the first nice spring day with lots of sun,” she said when reached in late March. “You saw everybody coming outdoors, looking around, watching the tulips. Sometimes you can’t tell who is a caregiver, who is a client and who is a family member. When you put them in a normal environment, they look healthy.”

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