

Pandemic adds to stress of patients with dementia and their caregivers

By LISA EISENHAUER

As if the illness and deaths caused by COVID-19 weren't bad enough, research shows the pandemic and precautions put in place in response have caused stress that has exacerbated the conditions of many nursing home residents with dementia and made caring for them more challenging for workers.



Sr. Di Maria

Sr. M. Peter Lillian Di Maria, O CARM, director of Avila Institute of Gerontology, and her Avila colleague Alfred Norwood shared what their review of the latest studies of long-term care center residents found during a CHA webinar in late January titled "Dementia Care during a Time of COVID."



Norwood

They also offered suggestions to help keep residents' mental function from declining and to address the heavier burden that has been placed on care centers' staff.

Studies done since the start of the pandemic clearly show what experts in nursing home care like her and Norwood have long known, Sr. Di Maria said. "Stressed residents with dementia are more dependent and behavioral," she said. "These increase both caregiver time and caregiver stress, which ultimately results in caregiver fatigue, compassion burnout, care staff turnover, and higher labor costs."

The research also has pointed to new findings such as that COVID can cause or worsen dementia, Sr. Di Maria and Norwood said. Among the studies that the pair referenced were:

- A survey done in April by medical

COVID worsens behavioral issues in patients with dementia

- Over 50% of nursing home residents have dementia
- After COVID, residents with dementia declined
 - 56% had increased behavioral issues
 - 34% had worsening cognition
 - 18% had functional decline
- COVID mortality increased with
 - Number of aided activities of daily living
 - Severity of dementia

Sources: "Facing Dementia During the COVID-19 Outbreak," *Journal of the American Geriatrics Society*, June 9, 2020, and "Risk Factors Associated With All-Cause Mortality in Nursing Home Residents With COVID-19," *JAMA Internal Medicine*, Jan. 4, 2021.

staff of 139 patients in Italy with dementia and cognitive disturbances that found that 54.7% of patients in the study group "experienced the worsening or the onset of behavioral disturbances, with agitation/aggression, apathy, and depression representing the most commonly observed manifestations."

- A survey of 4,913 caregivers of patients with dementia in Italy that found increased behavioral and psychological symptoms such as irritability and apathy in 60% of the patients after a month in quarantine due to the pandemic. It also found stress-related symptoms in two-thirds of caregivers. "Health services need to plan a post-pandemic strategy in order to address these emerging needs," the authors concluded.

- A look at best practices done by Canadian researchers that concluded that efforts should be made to address the psychological health of frontline health care workers and informal caregivers "as they are paramount to success" in dementia care amid the pandemic.

Less control, more dependence

Norwood discussed how changes

in activities and surroundings and loss of control over those things can lead to adverse reactions from patients with dementia. He identified new sources of stress related to COVID safety protocols, such as being confined to their rooms, cut off from in-person visits with relatives and cared for by people wearing masks.

"Stress triggers survival, fight-or-flight reactions in residents, making them either more dependent or more behavioral," he said.

He and Sr. Di Maria said the behavioral disturbances can take many forms, including hallucinations, delusions, agitation and aggression. Meanwhile, overwhelmed residents sometimes give up on or forget how to perform basic activities of daily living — such as brushing their teeth or feeding themselves — making them more dependent on care providers.

Norwood noted that while there are medications available that have been shown to slow the progression of some forms of dementia, there is no known medical treatment or pharmacological cure for the condition. He said most patients with dementia, nevertheless, are on some form of psychological medication, usually for

depression, anxiety or sleep disorders.

Those types of drugs can introduce additional concerns. Norwood said research has found psychotropic medications “often escalate rather than reduce adverse reactions or behaviors.”

Overlooking pain

Norwood said unmanaged pain is another cause of behavioral disturbances. Researchers say pain often goes unnoticed in patients with dementia and can be masked by symptoms of COVID. Identifying and effectively treating pain could go a long way in addressing behavioral issues, Norwood said.

Norwood said there are nonpharmacological means to keep patients with dementia calm and less likely to act out. Among those are creating a predictable, low-stress environment by keeping to strict schedules and routines, adjusting activity and lighting to those schedules

and improving sleep management.

Sr. Di Maria offered additional “low-labor interventions” that have been shown to put patients with dementia at ease, such as video visits with loved ones, regular exercise and aromatherapy.

“These are all activities that create cues to trigger retained behaviors, such as dancing, walking or singing along with very familiar songs,” she said. “So, the many things that we already know and do in our programs are also helpful now as we’re coming out of COVID.”

Overwhelmed staff

For the long term, Sr. Di Maria recommended that to meet the physical and emotional needs of residents nursing homes adopt a “relationship-centered” care model. In that model, staff works to build stronger bonds with residents, reach more definitive diagnoses of residents’ conditions and craft specific plans

for dealing with chronic issues for each resident.

Meanwhile, facilities should address the extra toll the pandemic has taken on staff, Sr. Di Maria and Norwood said. Workers should be given more training in how to use the interventions, how to problem solve so patients’ conditions don’t escalate and how to reduce their own stress through breathing and meditation techniques.

Research says such investments in staff will pay back in lowered expenses in the future; in less troubled staff, residents and families; and by aligning everyone “with the mission that each of us wants and that is giving the best possible care that each of us can based on what we know today,” Sr. Di Maria said.

A recording of the webinar is available to CHA members at chausa.org/online-learning.

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