

Most seniors with dementia live at home, despite pain, anxiety, poor health

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Contrary to popular belief, most older Americans with advancing dementia remain in their own homes—many until they die. But a new study by researchers at UC San Francisco has revealed that this population may endure more pain and have more complex or unaddressed medical needs than their counterparts in nursing homes.

In the study, researchers compared the medical characteristics of 728 adults over 65 with moderately severe dementia, in three settings: the participants' own homes; residential care, which spans the spectrum of retirement communities from those offering support at extra cost to assisted-living facilities; and nursing homes, which care for people unable to attend to their most basic needs.

Although the living-at-home participants had an average age of 82, four years younger than the nursing home residents, the researchers found that they had more chronic conditions—3.2 versus 3.1—were more likely to be bothered by pain—70.8 percent versus 58.6 percent—and had fallen in the last month or had concerns about falls—67.1

percent versus 50.4 percent. Additionally, they were more likely to have anxiety and fair or [poor health](#), rather than good or excellent health.

Seniors Turning Away from Nursing Facilities in Favor of Familiarity of Home

But the authors say the findings—which appear in the *Journal of the American Geriatrics Society* on Aug. 7, 2019—should not be interpreted as a call to accelerate moving people with moderately severe dementia from their homes.

"Rates of nursing home use are declining because they are expensive and people generally prefer the familiarity of home," said first author Krista Harrison, Ph.D., of the UCSF Division of Geriatrics. "People with dementia benefit from consistent and predictable environments and caregivers. Nursing homes may offer more people to help with medical and [social needs](#), but that might mean sharing a room with someone with different daily habits or distressing behavior symptoms."

In keeping with the trend away from nursing homes, Medicaid spending on community and home-based services has surpassed spending on institutional care, the authors noted.

The participants were drawn from a sample of Medicare enrollees, representative of seniors nationwide. Some 499 of the total participants lived at home (68.5 percent), 126 lived in residential facilities (17.3 percent) and 103 (14.2 percent) lived in nursing homes. In a 2015 study cited by the authors and drawn from a separate nationally representative sample of U.S. seniors, 58.7 percent with dementia were reported to have died in their homes.

To meet the criteria for moderately severe dementia, the study's participants had a doctor's diagnosis for dementia or were determined to have probable dementia according to a survey algorithm.

Additionally, they had to struggle with at least one activity of daily living, such as dressing, bathing or toileting, and a "cognitively-oriented instrumental activity of daily living," such as managing medications or finances.

"At this stage of dementia, patients may have difficulty recalling their address or personal history," said senior author Alexander K. Smith, MD, MPH, from the UCSF Division of Geriatrics and the San Francisco Veterans Affairs Medical Center. "Communication becomes impaired and the individual may struggle to follow a conversation and become disoriented with respect to time and place. They may lack good judgment and experience mood and behavior changes."

Seniors in residential facilities with moderately severe dementia differed from those at home and in nursing homes. This group, whose average age was 85, had less depression and anxiety, fewer chronic conditions and less unintentional weight loss. However, the cost of residential care facilities, which average \$48,000 a year, makes them prohibitive to most seniors for multi-year stays. While nursing homes are more expensive, depending on the state, Medicaid may cover seniors with particularly low income and assets, the authors said.

Seniors in Residential Care More Likely to Be Higher Income, Less Likely to Be Partnered

Not surprisingly, the seniors living in [residential care](#) had higher incomes and were more likely to be U.S.-born and have post-high-school education, compared to those living at home or in nursing facilities. Conversely, this group was significantly less likely to be married or living together (16.4 percent) compared to those living at home (45.1 percent) or in nursing facilities (21.8 percent).

Home-based medical care, in which insurance pays for coordinated home care provided by doctors, physician assistants or [nurse practitioners](#) and their interdisciplinary teams, is a small but growing portion of health care.

"Some people with dementia who live at home receive home-based primary, geriatric or palliative

care, but many more likely do not," said Harrison, who is also affiliated with the UCSF Philip R. Lee Institute for Health Policy Studies. "There is an urgent need for these services—as well as home health aides and other social supports—to become widely available to those families providing home care for loved ones with [dementia](#)."

Studies indicate that just 12 percent of homebound people receive primary care in their homes, according to the authors. Such programs result in reductions in disability and depression, fewer visits to emergency departments, fewer hospital stays and long-term care admissions, as well as positive impacts on caregivers' health.

More information: Krista L. Harrison et al, Care Settings and Clinical Characteristics of Older Adults with Moderately Severe Dementia, *Journal of the American Geriatrics Society* (2019). [dx.doi.org/10.1111/jgs.16054](https://doi.org/10.1111/jgs.16054)

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