

New data shows burden of dementia symptoms just as high in community population as nursing home residents

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New data shows that the symptoms suffered by people with advanced Alzheimer's disease and related dementias who live in the community

occur at a strikingly similar rate to those of dementia patients in a nursing home. The study from Regenstrief Institute and Indiana University School of Medicine is one of the first to look at dementia symptom prevalence in the community population.

Dementia currently affects about 5 million [older adults](#) in the U.S., and its incidence is expected to more than double over the next 40 years. More than 21 million people in the U.S. are providing unpaid care for someone living with dementia. Because there is no cure for the disease, the goal is to manage dementia symptoms to alleviate patient discomfort and reduce caregiver burden.

Researchers took baseline survey data from a five-year randomized clinical trial funded by the National Institute on Aging named IN-PEACE (Indiana Palliative Excellence in Alzheimer's Care Efforts) and analyzed responses from caregivers regarding symptoms.

The most common symptoms include:

- Pain
- Agitation
- Anxiety
- Resistance to care

"We found that both the rate and types of symptoms suffered by community-dwelling people with dementia were very similar to those in a nursing home setting," said first author Kurt Kroenke, M.D., Regenstrief research scientist and professor of medicine at IU School of Medicine.

"More than 40 percent of these people were experiencing these symptoms at least weekly. The symptoms are not subtle, they are not infrequent, and they do have a significant impact on the quality of life

for patients and caregivers," Dr. Kroenke continued. "However, they often go unreported in primary care settings. It's an area that requires more attention during routine care."

Regenstrief and IU School of Medicine researchers and clinicians are attempting to address this issue with palliative care interventions through the IN-PEACE trial. They are testing a collaborative care model using nurses and community health workers to help manage symptoms and provide caregivers with support.

"These baseline numbers will help us to see if palliative care eases the [symptom](#) burden," said senior author Greg Sachs, M.D., a Regenstrief research scientist and a professor of medicine at IU School of Medicine. "While we gather data from the clinical trial, this initial information shows the need for providers to make room for symptom discussion in primary care."

A unique aspect of IN-PEACE: more than 40 percent of enrolled subjects are Black. Dementia clinical trials often have 10 percent or a smaller proportion of subjects who are Black.

The research was published in the *Journal of Palliative Medicine*.

More information: Kurt Kroenke et al, Prevalence and Predictors of Symptoms in Persons with Advanced Dementia Living in the Community, *Journal of Palliative Medicine* (2022). [DOI: 10.1089/jpm.2021.0402](https://doi.org/10.1089/jpm.2021.0402)

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