

Living at home with dementia

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Most people with dementia who live at home have multiple unmet health and welfare needs, any number of which could jeopardize their ability to remain home for as long as they desire, new Johns Hopkins research suggests.

The researchers say routine assessments of patient and caregiver care needs coupled with simple fixes in the areas of safety—grab bars in the bathroom, carpets safely tacked down to prevent falls, guns locked away—and basic medical and supportive services could go a long way toward keeping those with [dementia](#) from ending up in a nursing or assisted-living facility.

"Currently, we can't cure their dementia, but we know there are things that, if done systematically, can keep people with dementia at home longer," says study leader Betty S. Black, Ph.D., an associate professor of psychiatry and behavioral sciences at the Johns Hopkins University School of Medicine. "But our study shows that without some intervention, the risks for many can be quite serious."

Previous research has shown that greater unmet needs among people with dementia are predictive of nursing home placement and death. Caregiver stress also foretells of nursing home admission for people with dementia. The new study, described in the December issue of the *Journal of the American Geriatrics Society*, also finds most caregivers have multiple unmet needs, including lack of access to resources and referrals to support services and education about how to best care for their loved one.

Black says that paying for needs assessments and putting into place preventive safety measures isn't always feasible, and programs like Medicare don't typically cover them. "If they did," she says, "it may be far more cost-effective than long-term [nursing home care](#)."

An estimated 5.4 million people in the United States have Alzheimer's disease and other types of dementia, and 70 percent are cared for in the community by family members and friends. Most have mild to moderate dementia.

For the study, Black and her colleagues performed in-home assessments and surveys of 254 people with dementia living at home in Baltimore and also interviewed 246 of their informal, non-professional caregivers. They found that 99 percent of people with dementia and 97 percent of their caregivers had one or more unmet needs. Ninety percent were safety-related. More than half of the patients had inadequate meaningful daily activities at a senior center or at home, and one-third still needed a dementia evaluation or diagnosis.

Unmet needs fell into many categories including safety, health, meaningful activities, legal issues and estate planning, assistance with activities of daily living and medication management, Black says.

More than 60 percent of people with dementia in the study needed medical care for conditions related or unrelated to their dementia, a problem considering that those with dementia are more likely to have other serious illnesses for which they may eventually be hospitalized, Black says.

"This high rate of unmet medical care need raises the possibility that earlier care could prevent hospitalizations, improve quality of life and lower the costs of care at the same time," she says. Interestingly, unmet needs were significantly greater in those with higher cognitive function,

most likely because many of them did not realize they had dementia and were not yet being closely cared for or monitored, Black says.

The researchers also found that African-Americans, those with lower income, those who were more independent in their basic daily living activities such as being able to feed and clothe themselves and those with more symptoms of depression had higher levels of unmet needs.

Caregivers with less education and more symptoms of depression also had significantly more unmet needs. This suggests that identifying and treating depression in people with dementia and their caregivers may enable them to address their other unmet needs.

Provided by Johns Hopkins University School of Medicine

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