

# Hospice improves quality of care in patients with dementia

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While the hospice program was originally designed for patients with cancer, who are expected to die within six months, currently close to half of older adult hospice enrollees have a diagnosis of dementia.

Now a new study by researchers at UC San Francisco and Icahn School of Medicine at Mount Sinai shows that hospice patients with [dementia](#) are more likely to receive excellent care and have their anxiety and sadness managed than those not on hospice. However, [eligibility criteria](#) mean that some patients with dementia face hurdles gaining access to hospice or may risk disenrollment.

In the study, publishing in *Health Affairs* on June 6, 2022, researchers tracked Medicare claims and data from the National Health and Aging Trends Study of 2,059 seniors over 70, who had died between 2011 and 2017. Some 40% of these seniors (951) had dementia, of whom 59% used hospice, which is defined as regular visits by nursing staff, social workers and chaplains provided at the patient's home, assisted living facility, nursing home, or dedicated area within a hospital or freestanding hospice. Of the 60% of seniors (1,108) without dementia, 43% used hospice.

Researchers compared quality of care in the last month of life between patients with dementia on hospice and patients with dementia not on hospice, by questioning their "proxy," a spouse or adult child caregiver in most cases, following the death of the patient.

Some 52% of hospice enrollees' proxies said the standard of care was excellent, versus 41% of proxies of non-hospice enrollees. Additionally, 67% of hospice enrollees' proxies said their sadness and anxiety was managed, compared to 46% of proxies of non-hospice enrollees. Results also showed the hospice enrollees were less likely to be switched to a different care setting than non-hospice enrollees in the days before their deaths: 10% versus 25%.

## **Impact of hospice care same for patients with and without dementia**

In comparing the proxy ratings of hospice for patients with dementia to patients with other conditions, the researchers unexpectedly found the impact on [quality of care](#) to be about the same.

First author Krista L. Harrison, Ph.D., an associate professor in the UCSF Division of Geriatrics and health services researcher, said she was surprised by this finding. "We honestly expected it not to be positive. Since the hospice model was designed for patients with cancer, we expected end-of-life care to be worse for people with dementia," she said.

Moreover, prior research indicates patients with dementia also risk disenrollment, in which care is terminated due to insurance reimbursement criteria that require documentation of continuous decline, she said. At the other extreme, concerns about disenrollment may mean patients with dementia are less likely to gain full benefit of hospice and enroll too late—if at all, the researchers say.

The philosophy of hospice assumes that the dying person is able to participate in decision making, and that family members provide care between visits of the hospice team. But to be eligible for hospice with a principal diagnosis of dementia, enrollees must be "unable to speak and need help with nearly all activities of daily living," Harrison said. Therefore, their needs surpass the help often available through the Medicare hospice model, leaving gaps to be filled by family, friends or paid caregivers.

### **Hospice policies should fit 'unpredictable trajectory of dementia'**

The hospice model "may result in both reduced access and paradoxically long stays, and high rates of disenrollment while still alive," said co-author Lauren Hunt, Ph.D., RN, FNP, a [nurse practitioner](#) and health services researcher at UCSF. "Hospice policies could be changed to

better fit the unpredictable trajectory of dementia," she said.

Harrison added that care in the last month of life may look no different than the prior six months until the final days. Many people with dementia die from conditions that may escalate rapidly, like a bladder infection or pneumonia. (Although the researchers did not quantify disenrollments in this study, a 2020 survey found that in the San Francisco Bay Area, 20.2 % of hospice enrollees with dementia were discharged before they died, compared with 13.9% of patients with cancer.)

In theory, enrollees are entitled to an unlimited number of days of hospice care, the researchers state. But in reality "regulatory changes and increased oversight" mean many hospice organizations are reluctant to enroll patients with dementia for more than "brink-of-death care," for fear they will not be able to document the continuous decline required for eligibility and insurance reimbursement. According to Harrison, "disenrollment can feel like abandonment because there are few adequate alternative models of near-death care for people with dementia."

The finding that hospice significantly benefits enrollees with dementia underscores the need to ensure access to high-quality end-of-life care for this growing population, she said. "Future work should examine whether removing prognostic requirements from [hospice](#) eligibility for people with dementia positively affects timely access and care quality."

Provided by University of California, San Francisco

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