Older persons with dementia report a lack of respect from home care services
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People with dementia disease receiving home care feel that they are not treated with the same degree of respect and dignity as people who do not have dementia and receive the same service. That is according to a study by researchers at Mälardalen University (MDH), Karolinska Institutet and Dalarna University, published in The Journal of the American Medical Directors Association.

"It is also remarkable that even when dementia is discounted, the experience of being treated with dignity and respect declined from 2016 to 2018," says Lena Marmstål Hammar, senior lecturer of caring sciences at MDH and the study's corresponding author.

The study also shows that people who receive extensive home care experienced worse treatment in terms of respect and dignity than people with fewer home care hours.

The research is based on national data from the National Board of Health and Welfare’s user survey, which contains responses from 271,915 individuals over the age of 65 who were in receipt of home care in 2016, 2017 and 2018.

Underscores need to develop the care for older people

The researchers argue that the results are valuable to the development of health and social care for older people, which during the current pandemic is especially relevant.

"Going by our results, it's important for home care managers to analyze what steps need to be taken to ensure that people with dementia are treated with respect," says study co-author Anne-Marie Boström, senior lecturer at the Department of Neurobiology, Care Sciences and Society, Karolinska Institutet. "This could include improving continuity of care, so that an older person is cared for by the same home care staff as much as possible. Another possible measure is to give staff more training in appropriate demeanor when meeting people with dementia."

Follow-up studies underway

Since the study is based on data gathered before the pandemic, the researchers are planning follow-up studies on how older people have experienced home care services at a time when restrictions such as physical distancing have been imposed.

"The National Board of Health and Welfare conducted a user survey last spring during the pandemic, which will enable us to follow up on our results," Boström says. "It will be interesting to see how many of the older people receiving home care responded to the survey and, of course, how people who received home care during the first wave of the pandemic experienced the quality of help and how they were treated by staff."

More information: Lena Marmstål Hammar et al.

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