Caring for people with dementia: Late diagnoses and high burden of care

There are currently around 1.7 million people with dementia in Germany, a figure which is set to rise to 2.7 million by 2050 according to estimations. However, there are serious shortfalls in the day-to-day care being provided to those affected, as recent research carried out at Friedrich-Alexander-Universität Erlangen-Nürnberg (FAU) and Universitätsklinikum Erlangen shows. The studies shed light on the fact that a diagnosis is often made very late, a high care burden is experienced by relatives and there is a lack of services available at the end of patients’ lives.

This is the first time that population-based data has become available about the care of dementia patients. The research is based on the Bavarian Dementia Survey (BayDem), which was conducted between 2015 and 2017 in Dachau, Erlangen, and Kronach and was funded by the Bavarian State Ministry of Public Health and Care Services. In the survey, researchers interviewed around 700 people with dementia and their relatives several times. They published their findings in five studies.

Delays in the diagnosis
The study carried out at FAU shows that dementia is often detected at an advanced stage of the disease. Around half of the patients surveyed received their diagnosis almost a year and a half after the initial symptoms appeared. However, early diagnosis is essential for people with dementia and their relatives, to enable them to make decisions themselves about any upcoming issues and to put measures in place that could have a positive impact on the progression of the disease.

Care: Women experience higher levels of strain as carers than men, and children more than partners
Around two thirds of people with dementia receive care at home from their relatives. The strain this places on carers often means that they also become ill and become the ‘second invisible patient’. A recent study at FAU shows which factors influence the level of strain felt by carers. The results indicate that women feel more strain than men and children of dementia patients feel more strain than their partners or spouses. The most difficult issue for relatives to deal with is when dementia patients’ behaviour changes or when everyday tasks start to become a challenge for them.

Relatives only rarely use services for support
There are a large number of services that provide support to relatives caring for people with dementia. However, they only rarely make use of these services, as an FAU study shows. Around 37 percent of respondents said that caring for a family member placed a great strain on them. Despite this fact, only 36 percent of respondents in rural areas used a nursing care service, and around 27 percent of respondents in urban areas. Services such as occupational therapy, day care, or domestic help are used even less.

People with dementia are neglected by the system before they die
What sort of care is provided for people with dementia in the final phase of their lives? What are the causes of death and where do these patients die? A recent study at FAU discovered severe deficits as there is a lack of appropriate palliative care for dementia patients. None of the patients in the study died in a palliative care unit or received specialist palliative care.
care before they died. As the concept of palliative care was developed for cancer patients, no evidence-based guidelines exist for dementia.

Dementia in care homes: Sedating drugs increase risk of falls
The move into a care home is often unavoidable when dementia reaches an advanced stage. Patients with dementia are often prescribed a wide range of medication in care homes due to their symptoms and accompanying disorders. Research carried out by FAU and Universitätsklinikum Erlangen discovered a correlation between the administration of central nervous system depressant drugs and the number of falls requiring medical treatment.

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