Elderly with dementia perceive nursing homes as prisons

Anne Kari Tolo Heggestad at Oslo and Akershus University College of Applied Sciences (HiOA), Norway, has conducted a study on nursing home residents with dementia and their relatives.

"My informants expressed the view that the setting and routines of the nursing home created feelings of imprisonment and homesickness," says Heggestad.

"For example, one resident said that she often felt as if she was in a prison without bars. It had to do with the environment of locked doors and bolts, such as those leading to the duty room and the kitchen, but also with the fact that she was totally dependent on help."

Heggestad's study is based on participant observation in two nursing home wards and on qualitative interviews with five residents with dementia and eight relatives of residents with dementia.

They must not be underestimated

Heggestad wanted to use her study to find their voice.

The object was to examine what they perceived as violations or threats to their dignity, and how health care personnel can respect this.

Heggestad emphasizes that we must not underestimate people with dementia.

"I think we often tend to make excuses for what they say. Even though they suffer from loss of memory, their feelings and experiences are real there and then," says Heggestad.

Feel disempowered

Both relatives and residents believe that being taken seriously is the most important factor for maintaining dignity.

The importance of co-determination in everyday life is an issue that concerns the residents more than the relatives.

"They feel disempowered, and during the interviews they often broached the subject of why they ended up in a nursing home. It became clearly apparent that this was not a decision in which they had been involved," says Heggestad.
"Elderly people with dementia are rarely involved in the decision-making process."

**Relieved to have found a place in a nursing home**

Relatives, on the other hand, were relieved when their parent or spouse was finally allocated a place in a nursing home, inside these locked doors.

Then they knew where he or she was. They did not realise that co-determination and freedom were so important to them.

The relatives in the study also mentioned how the lack of resources and the fact that health care personnel were more concerned with their tasks than with the patients may threaten the dignity of the residents.

For the patients, this means that not just their physical and medical needs, but also much of their need for social contact, are met by the staff.

**The all-important life story**

For residents with dementia to maintain their dignity, it is important that they be taken seriously, that they be involved in making decisions, and that they be accepted, concludes Heggestad in her study.

"We can do better at listening to what elderly people with dementia want and what needs they have, and not just make decisions over their head," she says.

Another important point is the importance in dementia care of knowing the life stories of individuals.

"By knowing parts of each resident's life story and what they have done, we can begin to see the person behind the disease. This makes it easier for health care personnel to sit down with them and hold a conversation," says Heggestad.

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Read the Norwegian version of this article at forskning.no [8]

Fact box

- Dementia is a general term for a group of brain diseases that usually occurs in elderly people.
- The usual symptoms are memory loss, impaired ability to perform everyday activities, language impairment, personality changes, and behavioural changes.
- Around 70,000 persons in Norway have a dementia disease. This figure will rise in ageing populations. Research shows that around 80 per cent of residents in nursing homes have dementia.

*Source: Norwegian Directorate of Health*

Oslo Metropolitan University [11]
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Dementia sufferers benefit from GPS
Early diagnosis will slow dementia
Activity can improve the health of dementia patients
Dementia patients take alternative medicines and forget about it
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Anne Kari Tolo Heggestad's profile
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