

## HTA-Report | Summary

# Concepts of care for people with dementia

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## Introduction

Approximately one million people in Germany currently suffer from dementia, which corresponds to a prevalence of 1.3 %. The strongest risk factor for dementia is age, and the prevalence of the illness rises substantially in older age groups, reaching approximately 13 % among 80- to 84-year-olds and approximately 33 % among persons older than 90. If these prevalence rates remain the same and current demographic trends continue, more than two million people – twice as many as today – will be suffering from dementia in Germany by the year 2050.

In the older population, dementia is the most frequent reason that people need long-term care. Providing care to individuals with dementia is a challenging task for family and professional caregivers alike. In addition to cognitive symptoms (loss of memory and orientation) and the progressive impairment of the ability to perform everyday and, in late stages, basic activities (e. g. using the toilet), persons with dementia often experience psychiatric symptoms (hallucinations, delusions), affective disorders (depression, emotional instability), and behavioural disturbances (aggressive behaviour).

Because most forms of dementia cannot be cured, the focus of treatment is to provide adequate care. Modern approaches attempt to focus on the needs of patients, such as helping them to maintain cognitive functioning, the ability to perform everyday tasks, and quality of life for as long as possible. In recent years, a variety of interventions to caring for dementia patients have been developed, many of which are based on the communication and interactions that take place between care givers and patients. Other concepts focus on environmental interventions or sensory stimulation. The distinction between nursing and therapeutic interventions is often blurry, since those that can be described as “therapy” are often performed by nursing staff or involve redesigning the care-setting.

## Research questions

Currently there are no uniform standards for assessing the effectiveness of nursing interventions in patients with dementia. Most of the studies conducted to date have investigated areas such as cognition, functioning, quality of life, and social behaviour. Therefore, the objective of this health-technology assessment (HTA) is to perform a comparative evaluation of the different nursing interventions and their endpoints as described in the included studies. More specifically: what is the evidence on different approaches to the long-term usual care of patients with dementia in terms of common endpoints such as cognition, functioning, quality of life, and social behaviour?

For the economical part, the cost-effectiveness of the different interventions is evaluated.

In addition, this HTA aims to provide a brief overview of the ethical questions currently under discussion in the treatment of persons with dementia.

From a legal standpoint the situation of patients and usual care givers will be changed though the introduction of a new law, called “Pflege-Weiterent-

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Within the scope of the



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wicklungsgesetz“. Other questions concern the legal capacity and the capacity for delicts of people with dementia.

## Methods

A systematic review of the literature and a hand-search by the authors are performed. Also institutions and persons doing research in the area of usual care for dementia were contacted. At the same time the search does not claim completeness. Randomised, controlled studies are included, if they have at least 30 participants and investigate one or more of the following approaches to the management of dementia: validation therapy/emotion-oriented usual care, ergotherapy, sensory stimulation, relaxation techniques, reality orientation therapy, and reminiscence therapy. Studies have to be published after 1996 (after 1989 for the economical part) in English or German. No restrictions are defined with regard to the endpoints under investigation. However, studies with less than 30 patients are excluded, as are any interventions that are not conducted chiefly by nursing staff. All studies are selected independently by two researchers according to predefined inclusion and exclusion criteria.

## Results

Using a list of search terms, a total of 1,658 clinical, 665 economic and 35 ethical/legal studies are identified. Following a review of the abstracts, 287 of the former and 213 of the latter are marked as being potentially relevant. Of the 287 clinical studies, a total of 20 fulfils the predefined inclusion criteria and are included in the present HTA. Also five economical studies are included.

These 20 publications are based on 19 studies. Eight studies are conducted in the United States, four in the Netherlands, four in Great Britain, one in Italy, one in Canada, and one in China. One study is based on data from three different countries (i. e. Great Britain, the Netherlands, and Sweden). Of these 20 studies, three focused on validation therapy/emotion-oriented care, five on ergotherapy, seven on different kinds of sensory stimulation, two on reality orientation, two on reminiscence therapy, and one on a type of relaxation technique.

No significant differences are reported between the intervention and control groups in two of the three studies on validation therapy or emotion-oriented usual care, in two of the five studies on ergotherapy, in three of the seven studies on sensory stimulation, in both studies on reminiscence therapy, and in one study on relaxation. In the remaining ten studies, seven report some positive results in favour of the respective interventions, and three studies (ergotherapy, aroma therapy, and music/massage) report positive effects with respect to all of the measured endpoints.

Six publications present economic results for care-concepts. The studies originate from Italy, the United Kingdom, the USA and Germany. The British study reports additional costs of 16 GBP (24.03 Euro (2006)) per patient per week for occupational therapy, while there are no significant differences in the clinical endpoints. Two separate publications refer to the Italian study and report incremental costs of 24.30 USD (25.62 Euro (2006)) per MMSE-point gained per month and 1,380,000 ITL (506.21 Euro (2006)) per MMSE-point gained respectively. The publications from the USA and Germany focus on mixed interventions. The former reports the additional costs of an activity program (1.13 USD (1.39 Euro (2006)) per day per patient) and the later an average of 45 additional minutes per day per patient spent for the care for mobile demented patients.

## Discussion

Few of the studies on the nursing interventions considered in this report are methodologically robust. Most of the studies have a small number of participants and show substantial methodological differences. Heterogeneity results from differences in the severity of illness within and across study populations, in the extent and implementation of the various interventions, in the type of control groups (e. g. usual care or alternative intervention), and in study duration. Moreover, the studies assess a variety of endpoints using different questionnaires which limits the comparability of the results even further.

This heterogeneity in methodology may be the reason for the heterogeneity seen in the results: in half of the studies the interventions have no positive effects compared to the control group. The other half of the studies reported some positive effects, albeit with regard to different endpoints. All of the economic studies are not suitable to answer the questions raised.

## Ethical, social and legal considerations

Ethical considerations for patients with dementia focus on the autonomy of subjects, especially with respect to informed consent. A diagnosis of dementia does not necessarily preclude the competence for an informed consent. Because no specific methods for assessing competency in dementia have been established, it has to be considered on an individual basis. If the decision to participate in a study is made by a proxy, researchers have to ensure that this decision is based on prior values of the patient. Moreover, possible risks of participation in a study have to be weighted against possible benefits.

The legal situation in Germany has changed just recently. A law, called "Pflege-Weiterentwicklungsgesetz", is intended to improve not only the financial situation of but also the support for patients and usual care givers. Another legal question concerns the legal capacity respectively the legal representation of people with dementia. Depending on the progress of the illness, people with dementia lose their capacity to legally represent themselves and therefore cannot for example sign binding contracts. In this case there are two possibilities: a judge assigns a legal guardian or the demented person appoints someone prior to losing the capacity for legal representation. Furthermore people with dementia will probably also lose their capacity for delicts. Therefore they cannot be held liable for their acts. If the person with dementia causes damages, it is possible, that the victims are not compensated.

## Conclusion

The studies conducted to date do not provide sufficient evidence of efficacy for any of the nursing methods considered in the present HTA. Lack of evidence however, does not necessary imply a lack of efficacy, but rather points to the need for additional and methodologically robust studies. These studies should take into account the conditions of dementia care in Germany. This holds also for the health economic evaluations of the chosen interventions.