

**Palliative Care for people suffering from dementia and
living in a nursing home in the canton of Zurich
(Pallhome Study)**

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Management Summary

Background: About 1.3% of the Swiss population currently suffers from dementia. This figure will rise to about 2.5% by 2030; 39% of those people currently live in a nursing home in Switzerland. Figures from the U.S. and Europe indicate that most people suffering from dementia die in a nursing home. This could also apply to Switzerland, but detailed data regarding patients with dementia and the place of the patients' death is so far not available. It is said that people suffering from dementia and living in a nursing home receive unsatisfactory care in the terminal phase. However, there is no data for Switzerland on this specific problem. Furthermore, there is no international data on how nursing staff make clinical decisions regarding successful relief of symptoms for people suffering from dementia. The purpose of this study is thus to examine the decision-making process in the terminal phase as regards successful symptom relief for people suffering from dementia and living in a nursing home.

Method: Sixty-five nursing records from four nursing homes in the canton of Zurich which document the last 90 days of patients' lives were evaluated regarding recurrent nursing problems with a retrospective-descriptive, mixed-method design, and were divided into four sections (S1: Days 90-61, S2: Days 60-31, S3: Days 30-8, S4: Day 7 – Day of death). Along with this, 32 semi-structured one-on-one interviews with nursing staff were conducted and analysed on the basis of Charmaz' Grounded Theory method.

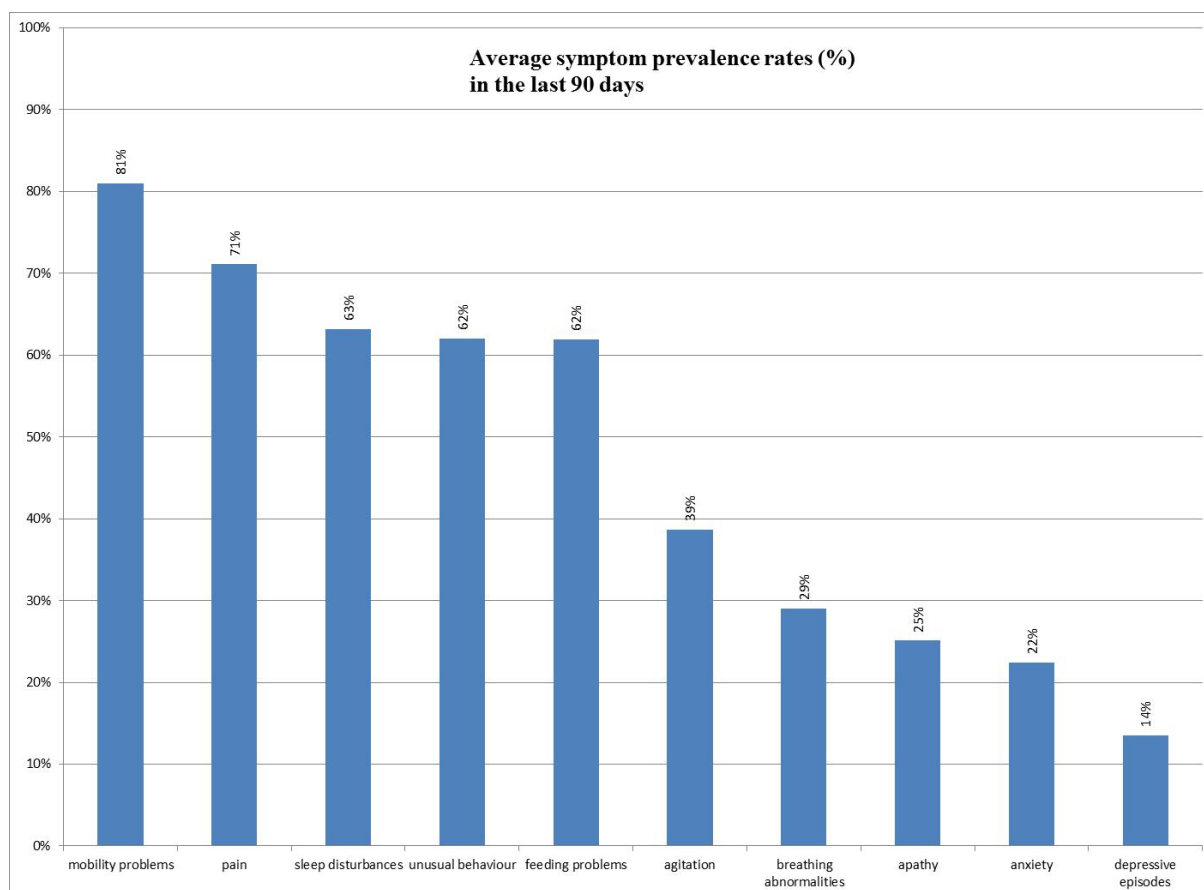
Results: Ten frequent nursing problems with two symptom patterns of increasing and decreasing tendency were identified during the last ninety days of life in people suffering from dementia and living in a nursing home (see Figure 1). Symptom pattern 1 has an increasing frequency between sections 1 and 4 and includes anxiety, apathy, shortness of breath, dietary problems and pain. Symptom pattern 2 has a decreasing frequency between sections 1 and 4 and includes "non-specific provocative behaviour", limited mobility, sleeping disorders, agitation and depressive episodes. Major nursing problems that every second person suffers from include pain, "non-specific provocative behaviour", limited mobility and sleeping disorders. Here, pain has a special status, as it is the only major nursing problem that continually increases within all four sections.

Most people with documented occurrences of pain receive pain medication (chi-square $p=.000$, Fisher's exact test $p=.000$, $\phi=.702$).

Paracetamol and morphine were the second and fourth most prescribed long-term

medications respectively. Morphine was the most common reserve medication out of the five types of reserve medication. It was striking that the group of over 86-year-olds received morphine as reserve medication significantly more often than the younger patients (Mann-Whitney U-test=28.000, $p=.028$). There was no significant difference in prescriptions given in nursing homes and by family doctors.

Figure 1: Frequent nursing problems



The ten nursing problems identified do not differ from the nursing problems described in the literature about people suffering from a tumour. The decisive difference is the complex process of interpreting indications, the process of “ascertaining” in order to achieve sustainable symptom relief. A continuous “reporting and reflecting” on perceptions and observations is necessary for the “ascertaining” process. This process is carried out by involving staff members with a high level of social and professional competence, as well as the whole team and relatives, and is influenced by time availability as well as the infrastructure of the nursing home and the attitude of the nursing staff. The basis of the decision-making process is thus the “reporting and reflecting”.

In order to “ascertain what could help” in the case of people suffering from dementia in the terminal phase, the nursing staff need an extremely differentiated pattern of perception that includes observing facial expressions, gestures and muscle tone and adjusting proximity and distance. The recognition of the acute dying phase demonstrates the degree of “solicitude for” the people suffering from dementia shown by the nursing staff. 75% of people suffering from dementia are visited daily or almost daily by their relatives in their last seven days of life. In order to achieve this high frequency of daily visits in the last week of life, it is necessary for nursing staff and relatives to continually exchange information on their observations.

However, successful symptom relief depends not only on respecting the patient’s autonomy, the “solicitude for” the patient’s welfare and the exchange in the team, but also on the quantity and the quality of the nursing staff’s clinical knowledge (see Figure 3). Clinical knowledge is characterised by technical know-how, theoretical knowledge and the ability to adjust interventions individually and according to the particular circumstances. The fact that – despite interventions – at least 64% of all patients affected suffer from pain in their last ninety days of life clearly shows that the symptom relief was not adequate.

Conclusion: Two symptom patterns for ten nursing problems in the last ninety days of life were identified. The main nursing problem is pain which, despite interventions, continually increased in all four sections. In order to achieve adequate symptom relief, extensive expertise by well-trained and experienced specialists is crucial in the clinical assessment, in the decision-making process and in the choice and implementation of interventions. Specialised nursing professionals with a MSc – so-called Advanced Practice Nurses (APN) – are qualified to achieve effective and lasting symptom relief that goes beyond the reporting and reflecting process. Since it is crucial for the symptom relief that the nursing staff know the people suffering from dementia, APNs should work in the immediate environment of primary care, in the nursing home.

Practice recommendations: In future, the improved options in domestic care will tend to reduce the time span for getting to know those people suffering from dementia. Therefore, it is even more important to strengthen the narrative interpretation competence. This can be achieved by methodical and substantive development of communication possibilities, such as reports, case conferences, family sessions and expert discussions.

Vocational education recommendations: Health experts (Fachfrauen/Fachmänner Gesundheit EFZ, so-called “FaGe”) and nursing care experts (Fachfrauen/Fachmänner Betreuung, so-called “FaBe”) play a significant role in the care of people living in nursing homes. Due to their social skills, they are well suited to pursuing nursing training at Bachelor of Science level.

Research recommendations: According to numerous studies, there are a multitude of non-pharmacological and pharmacological intervention options against acute and chronic pain. The aim of the study based on the “pain” nursing problem was to ascertain whether the employment of APNs leads to significant pain relief in people suffering from dementia.

Policy recommendations: The results of the study show that the employment of a large number of committed and motivated staff members with a caring attitude is not sufficient. People suffering from dementia and their relatives require well-educated professionals in nursing homes.