

SUMMARY

Chapter 1

Dementia is a progressive and life-limiting disease characterized by a gradual impairment of mental function. In the Netherlands, most patients with dementia are admitted to a nursing home at some point in the course of the disease. Patients with dementia often develop burdensome complications including infections such as pneumonia. At the end of the 19th century, pneumonia was described as “the old man’s best friend”. At that time, there was no cure for infections, and pneumonia seemed to offer a swift and painless end of life. However, respiratory infections have been associated with symptom burden in patients with dementia, and a Dutch study conducted in the late nineties showed the presence of severe discomfort for patients with dementia and pneumonia in nursing homes. Patients with a pneumonia are mostly treated with antibiotics. However, little is known about the actual effects of antibiotic treatment on (long-term) survival and comfort. Evidence on methods to relieve symptoms specifically for patients with dementia and pneumonia was still lacking, and no studies have used evidence- or consensus-based guidelines to intervene in discomfort.

Intervening into usual care may result in more adequate symptom relief and thereby improve patient outcomes. The study described in this thesis addresses the development, implementation and evaluation of a practice guideline for optimal symptom relief for patients with dementia and pneumonia. This practice guideline aimed at reducing discomfort, (lack of) comfort, pain and shortness of breath (in short: discomfort and symptoms) in patients with dementia and pneumonia in Dutch nursing homes.

Chapter 2

This chapter reports on the results of a systematic review of the literature on the prevalence of antibiotic use and on factors associated with antibiotic use in patients with dementia. The 24 articles that addressed prevalence of antibiotic use examined point prevalence, period prevalence, antibiotic use in the last period before death, or antibiotic use during a specific infectious episode. Overall, antibiotic use was substantial, but also varied widely between different settings and countries. For the treatment of specific infections such as pneumonia or urinary tract infections, antibiotics were provided in the majority of cases. Twenty-three articles described one or more factors associated with antibiotic use in patients with dementia which concerned the patient’s health status, persons involved in decision making, and the healthcare context. Only few factors were addressed in more than one study. More severe dementia was consistently associated with fewer antibiotic use. Associations with aspiration,

illness severity, and a number of healthcare contextual factors differed by country. For example, with increasing illness severity US patients were more likely to receive antibiotic treatment while this was associated with fewer patients treated with antibiotics in the Netherlands. The review provides a basis for further research and an international discussion among stakeholders about the ethical and practical considerations of providing antibiotic treatment in patients with dementia.

Chapter 3

This chapter uses data gathered in the pre-intervention phase of the trial among patients with dementia and pneumonia in Dutch nursing homes. It describes the course of discomfort, (lack of) comfort, pain and shortness of breath from pneumonia diagnosis until cure or death within two weeks. From the day of pneumonia diagnosis, daily observations were scheduled until day 10, and one last observation was scheduled on day 13, 14 or 15. Independent observers who were unfamiliar with the patient's condition and treatments performed the observations using four observational instruments. Discomfort was highest at the day of pneumonia diagnosis or the day after that, then declined, and was stable after ten days. Pain and shortness of breath followed a comparable pattern. Discomfort did not differ between patients treated with or without antibiotics. When death neared, more patients were observed asleep which could be a result of the disease itself, daytime sleep or e.g. palliative sedation. Discomfort strongly increased in the days preceding death, but only for the patients who were observed awake. The discomfort observed in the pre-intervention phase was low compared to observations in a previous study in Dutch nursing homes. Moreover, more symptom-relieving treatments were initiated, and patients appeared to be in a better health condition than before. Future studies should examine what treatments are the most effective in relieving pneumonia symptoms, in particular in the days preceding death.

Chapter 4

This chapter describes the development of an intervention to relieve pneumonia symptoms in patients with dementia: a practice guideline for optimal symptom relief. Initially only one qualitative round was planned in which experts were asked to provide feedback on a first version of the practice guideline. However, little evidence available and different clinical views led to much more variation in expert opinion than anticipated. An adequate solution to reach consensus was a Delphi procedure. With a Delphi study, consensus can be reached in a panel of experts, while their identities are kept confidential, thereby avoiding dominance of one expert over the other. The Delphi with 24 (inter)national experts in the fields of elderly care medicine, palliative care,



infectious disease, general practice, nursing and pharmacy comprised three qualitative rounds and two quantitative rounds. The topics on which opinions diverged the most in the first two rounds were addressed in 40 statements, which were about care goals, the use of guidelines for palliative care developed for other diseases, treatment of rattling breath and sputum retention, and about a number of specific treatment options. The experts rated their agreement with the statements on a 5-point Likert scale after which consensus was determined using pre-defined criteria. Eighty percent of the statements reached moderate consensus. Divergent opinions remained for the topics of usefulness of oxygen administration and the treatment of rattling breath. For these topics, the project team decided. Moreover, views of Dutch experts were in some of the cases given more weight than the opinion of international panel members. As a result, certain recommendations should be reevaluated if the guideline were implemented in other countries than the Netherlands. The final version of the practice guideline consisted of three components: a checklist of symptoms, observational instruments to monitor symptoms and tailored treatment recommendations. The practice guideline was expected to enhance comfort by enhancing awareness with regard to comfort, by regular observations to monitor symptoms, and by providing a more structured treatment approach.

Chapter 5

This chapter addresses the results of a cluster randomized trial in 32 Dutch nursing homes. The effects of a practice guideline for optimal symptom relief were assessed on discomfort, (lack of) comfort, pain, and shortness of breath. In a pre-intervention phase, care as usual was provided. After this phase, nursing homes were assigned to either the control group or the intervention group. Patients in the control nursing homes received care as usual, while the practice guideline for optimal symptom relief was introduced in the intervention homes. The practice guideline was not effective in reducing discomfort and symptoms in this study. Only for patients who did not die within twenty days, the intervention enhanced comfort to some extent. Regardless of the intervention, discomfort and symptoms were higher for patients who died within twenty days following pneumonia diagnosis, and lower for patients who were observed asleep. Discomfort and symptoms were higher in the pre-intervention phase than in the intervention phase, and gradually decreased throughout the 3.5 years of collecting data for both the control homes and the intervention homes. Control homes may have attempted to do better out of sense of competition. The gradual decrease may be explained by an increased focus on comfort and palliative care in media and education, or by the awareness created by the study itself – i.e. the regular observations. It is therefore hypothesized that an intervention that is multidisciplinary, directed at awareness of discomfort and regular observations by the nursing staff may

be more effective than a physician practice guideline.

Chapter 6

This chapter reports on a mixed-methods process evaluation that was performed alongside the trial, to evaluate the processes that took place in the participating nursing homes. The process evaluation helped in the search for an explanation for the lack of an intervention effect. The practice guideline for optimal symptom relief was introduced in 1-hour meetings in each nursing home in the intervention group at the start of the intervention phase. Collected data included two quantitative questionnaires on the patient and physician level, and semi-structured interviews with physicians who did, or did not use the practice guideline. Physicians indicated to have consulted the practice guideline for the treatment of the majority of patients in the intervention group. However, actual use varied for the different intervention components (i.e. the checklist, the observational instruments, and treatment recommendations). For example, observations using the observational instruments for pain and shortness of breath were rarely performed, while these were one of the possible ways the guideline could enhance comfort. Physicians were generally satisfied with the contents of the practice guideline and perceived it as a good overview of current practice. The most prominent barrier was physician's feeling they already worked according to the guideline, as the guideline did not contain new or innovative information. On the other hand, some physicians had difficulties to (re)familiarize with the contents of the guideline every time, and lacked time to do so in case of acute illness. The hectic pace of the nursing home was also regarded a barrier for using the guideline. Overall, the lack of an intervention effect may be explained in two ways: 1) by a modest effect of the implementation procedure and 2) the guideline deviating little from current practice. More effect of an intervention for optimal symptom relief in patients with dementia and pneumonia may have been achieved with a more practical intervention rather than a practice guideline, or with the application of more intensive or evidence based implementation strategies.

Chapter 7

The general discussion in this chapter provides a summary of the study's most important results, and a number of methodological considerations, such as the diagnosis of pneumonia, working with observational instruments and (independent) observers to assess the outcomes, and the development of the intervention. Reflections on the study's findings highlight that discomfort was low compared to what was observed in a previous study that assessed discomfort in patients with dementia and pneumonia. Discomfort increased with nearing death, and was high compared to findings in an-

other study. The discussion also elaborates on the possible explanations for the lack of an intervention effect, and on the gradual decrease of discomfort and symptoms throughout the study. Implications of the study's results for practice include 1) the use of observational instruments by nursing staff for earlier detection of symptoms and more adequate symptom relief, and 2) creating awareness about the presence of discomfort, about important considerations regarding the prescription of antibiotics, and about the need of adequate symptom relief before death. For further research, suggestions are focused on factors associated with antibiotic treatment, discomfort in the days before death, and approaches that might lead to more successful reduction of discomfort and symptoms in patients with dementia and pneumonia than the practice guideline and implementation procedure described in this study.

The practice guideline for optimal symptom relief was the first evidence- and consensus-based intervention that aimed to reduce discomfort and symptoms for patients with dementia and pneumonia. In its current form, however, the guideline had no added value over usual care. The research presented in this thesis, again stresses the importance of comfort for patients with dementia and pneumonia, and shows that there was still room for improvement. On the other hand, comfort in patients with dementia and pneumonia has increased over the years, and also the number of treatments initiated to relieve pneumonia symptoms. Furthermore, discomfort and symptoms gradually declined during the data collection of the study in this thesis. These very favorable developments that occurred in a time span of 15-20 years between studies, and in 3.5 years during this study, are both likely attributed to creating awareness about the subject of discomfort – in any form. Further research should take the concept of awareness as a starting point to continue the search for the best way to provide ultimate symptom relief and comfort for patients with dementia and pneumonia.