SUMMARY

The framework for this thesis and a general introduction to palliative sedation can be found in **Chapter 1**. Palliative sedation is defined as the deliberate lowering of the consciousness of a patient in the last stage of life. The aim is to relieve the suffering of the patient, whereby reducing the consciousness is a means to achieve that goal. Aim of this thesis is to assess whether the RDMA guideline for palliative sedation in the Netherlands is being followed. Different settings are included to get a broad overview of the practice. In addition, both physicians and nurses are approached to see whether any differences in perception between these two groups of caregivers exist. Moreover we examine if (and if so which) obstacles in the current practice of palliative sedation are present in the perception of the nurses. Furthermore we hope to identify factors that may lead the course of palliative sedation in to a desirable outcome. Finally, we aim to evaluate the possibility of clinical monitoring of the depth of palliative sedation by palliative care nurses.

As part of the describing the practice of palliative sedation the main results of the AMROSE study are dealt with in **Chapter 2**. A sample of 1580 physicians and 576 nurses were asked to fill in a questionnaire concerning about their last patient whom received continuous palliative sedation until death. The questionnaire was returned by 606 physicians and 278 nurses of whom 370 doctors and 185 nurses did recall a recent case. Main conclusions in this chapter are that continuous palliative sedation until death usually is initiated based on the refractory physical symptoms. However non-physical symptoms seem to contribute to the clinical picture as well. In addition, it seems that doctors and nurses have different experiences with regards to the decision to start palliative sedation. A clear form of communication is recommended to prevent these differences in perspective.

Chapter 3 discusses the evaluation of the current practice of palliative sedation in a home situation after introduction of the RDMA guideline from the perspective of the Medical Technical Assistance (MTA) nurses. Using a structured questionnaire offered online 170 MTA-nurses gave insight into the awareness of the directive, decision-making and running a practice being centred in medication and treatment policies, communication between workers, with the patients and their relatives, and reporting. Results from this exploratory study show that current practice is largely in accordance with the RDMA guideline with respect to the indication for palliative sedation and reportage. However, this survey identified shortcomings in medication policy, communication, medical control over the start and continued monitoring of palliative sedation. It is concluded that improvements are to be designated in the field of medication policy, a more multidisciplinary communication between healthcare workers and the transfer of information to the patient and his relatives. As MTA nurses have the opportunity to take independent decisions, special attention should be given to their (legal) protection and status during a palliative sedation.

Based on the respondents who had put forward a case of palliative sedation in the AMROSE study a distinction was made in **Chapter 4** in a group of respondents in which the outcome of the sedation was considered favourable (n=99 physicians, respectively 35 nurses' cases), and a group in which the outcome was less favourable (n=232 physicians, respectively 150 nurses' cases). Favourable outcome was defined based on directives from the RDMA guidelines, meaning an adequate relief of refractory symptoms, a good to very good quality of death and the absence of adverse events during sedation were considered to be an adequate outcome. Patients in cases presented with a favourable outcome of palliative sedation tend to be associated with a (relatively) shorter time to reach the required depth of sedation. In addition a clear primary indication and a stable course of benzodiazepines and opioids seems to be more prevalent amongst patients that had a favourable course. We concluded that these indications might provide caretakers with an indirect reference with regard to the probability of a favourable course.

Results of a qualitative study that describe the current practice of palliative sedation after the introduction of the RDMA guideline, are discussed in **Chapter 5**. After completing the questionnaire from the AMROSE study, 35 nurses gave permission for a semi-structured interview. This interview was an opportunity to explore themes discussed in the questionnaire more deeply based on the view of these nurses. In this chapter focus was put on factors that played a role in determining the depth of sedation during palliative sedation. The interviews were recorded and typed verbatim and coded for recurring themes. Nurses consider a deeper form of sedation as the only true form of palliative sedation, although some mention relief of symptoms as the main goal when maintaining the consciousness of a patient was an important consideration. They seem to differ in their views on the desired level of sedation that is sufficient to reach this deeper form of sedation.

Chapter 6 contains a systematic review conducted with the aim to describe developments in the scientific field of palliative sedation. The emphasis in this review was put on the use of monitoring scales, which could be used to assess the degree of control of refractory symptoms and/or the depth of the sedation. A database search up to January 2010 yielded in 30 relevant articles describing studies using evaluations or guidelines with information about the control of palliative sedation. Most studies have focused on monitoring of refractory symptoms (including pain, fatigue or delirium) or the level of conscious sedation to control. A minority of studies (n=4) described the use of observational scale to determine the effect of palliative sedation to control. It was concluded that future studies should focus more on establishing proper instruments that could evaluate depth of sedation and/or symptom control during palliative sedation. Attention should be paid to an interdisciplinary evaluation of these measurements, frequency of measurements and the most appropriate time to measure.

Chapter 7 shows the results of a prospective research, which aimed to study the reliability and validity of 4 observer-based sedation scales in palliative sedation. These scales (Minnesota Sedation Assessment Tool (MSAT), the Richmond Agitation-Sedation Scale (RASS), the Vancouver Interaction and Calmness Scale (VICS) and sedation score proposed in the RDMA guideline) are used to assess the depth of sedation during palliative sedation. 54 patients, who were sedated continuously or intermittently, were assessed by 52 different nurses whom at various times during the sedation monitored the depth of sedation. Inter-rater reliability was tested with the Intraclass Correlation Coefficient (ICC) and Cohen's Kappa coefficient. Correlations between the scales using Spearmans' rho tested concurrent validity. This study shows that RASS and KNMG scales stand as the most reliable and valid among the evaluated scales. In addition, RASS was less time consuming, and more clear and easy to use than MSAT and VICS. It is concluded that further research should focus on to evaluating the impact of the scales on better symptom control and patient comfort.

The conclusions and discussions of the previous chapters are presented in **Chapter 8**. The findings are discussed in light of earlier (inter)national research and looked at what lessons can be drawn from this thesis. The chapter ends with the main conclusions and recommendations.