Review Article

The Experiences of Relatives With the Practice of Palliative Sedation: A Systematic Review

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Abstract

Context. Guidelines about palliative sedation typically include recommendations to protect the well-being of relatives.

Objectives. The aim of this study was to systematically review evidence on the experiences of relatives with the practice of palliative sedation.

Methods. PubMed, Embase, Web of Science, PsycINFO, and CINAHL were searched for empirical studies on relatives' experiences with palliative sedation. We investigated relatives' involvement in the decision-making and sedation processes, whether they received adequate information and support, and relatives' emotions.

Results. Of the 564 studies identified, 39 were included. The studies (30 quantitative, six qualitative, and three mixed methods) were conducted in 16 countries; three studies were based on relatives' reports, 26 on physicians' and nurses' proxy reports, seven on medical records, and three combined different sources. The 39 studies yielded a combined total of 8791 respondents or studied cases. Caregivers involved relatives in the decision making in 69%−100% of all cases (19 quantitative studies), and in 60%−100% of all cases, relatives were reported to have received adequate information (five quantitative studies). Only two quantitative studies reported on relatives' involvement in the provision of sedation. Despite the fact that the majority of relatives were reported to be comfortable with the use of palliative sedation (seven quantitative studies, four qualitative studies), several studies found that relatives were distressed by the use of sedation (five quantitative studies, five qualitative studies). No studies reported specifically about the support provided to the relatives.

Conclusion. Relatives' experiences with palliative sedation are mainly studied from the perspective of proxies, mostly professional caregivers. The majority of

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relatives seems to be comfortable with the use of palliative sedation; however, they may experience substantial distress by the use of sedation. J Pain Symptom Manage 2012;44:431–445.

Key Words
Palliative sedation, relatives, experiences, systematic review

Introduction

During the last decades, death as the result of acute diseases largely has been replaced by death from chronic diseases,[1] resulting in an increased need for end-of-life care. In some cases, patients who are approaching death experience refractory symptoms that are difficult to alleviate despite intensive medical treatment.[2,3] This sometimes requires a treatment of last resort: palliative sedation.[3] Palliative sedation entails the use of sedating drugs to induce a state of decreased consciousness until death.[4]

It is known that palliative sedation is frequently used in end-of-life care. A study in six European countries reported that it was used in 2.5%–8.5% of all deaths.[5] Dutch nationwide studies showed that palliative sedation is increasingly used in The Netherlands, up to 8.2% of all deaths in 2005.[6,7] Palliative sedation is used in all settings where patients die, but most often in hospitals and for patients with cancer.[5,8–11] Within palliative care settings, incidence estimates of the use of sedatives prior to death range from 15% up to more than 60% of patients.[12–16] It is usually recommended that for the use of palliative sedation, the patient's disease should be irreversible and advanced, with a life expectancy of, at most, two weeks; benzodiazepines should be the drug of first choice; artificial hydration should only be offered to sedated patients when the benefit will outweigh the harm; the sedation should not be intended to hasten death; and advice from palliative care specialists should be sought before initiating the use of sedation.[4,17]

To guide caregivers, several international, national, and local guidelines for the use of palliative sedation have been published.[18] These guidelines typically also include recommendations to protect the well-being of relatives of patients who receive palliative sedation. In 2009, the European Association for Palliative Care introduced a 10-item framework for the development of institutional guidelines for the use of palliative sedation.[17] In 2005, the Royal Dutch Medical Association published a national guideline for palliative sedation in The Netherlands, which was revised in 2009.[4] Guidelines have been published in other countries also, for example, in 2005, a clinical guideline for palliative sedation was constructed in Japan.[19] According to these guidelines, relatives should be involved in the decision making, for example, by discussing the decision to sedate. Furthermore, relatives can be involved in the provision of the sedation, for example, by spending time with and observing the patient and providing physicians and nurses with information about the patient. Relatives should be kept informed, at various points in the course of palliative sedation, of the patient's well-being and what to expect; and the care team should communicate with the relatives in a language they can understand. The care team also must provide supportive care to the relatives by comforting them and lending a sympathetic ear to help them cope with the experience.

How these recommendations relate to the actual experiences of relatives has never been systematically investigated. The aim of this study was to systematically review evidence on the experiences of relatives with the practice of palliative sedation.

Methods

Search Strategy

A search strategy was developed for finding relevant publications in electronic literature databases. In November 2010, five electronic databases were searched (PubMed, Embase, Web of Science, PsycINFO, and CINAHL) using the