Clinical Note

Exploration of Concerns of Relatives During Continuous Palliative Sedation of Their Family Members with Cancer

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Abstract
Data on the experiences of relatives during *continuous palliative sedation are scarce. Because these relatives may be the ones most closely involved with the patient, it is important to evaluate the possible burdens that they experience. We aimed to explore and evaluate concerns of relatives during continuous palliative sedation of their family members admitted to an acute palliative care unit. Through retrospective multidisciplinary record research, we obtained data on concerns of the relatives during the period that continuous palliative sedation took place. From October 2001 to October 2004, 45 patients died after starting continuous palliative sedation. In 51% of the cases, the relatives expressed concerns after starting the therapy. Concerns could be distinguished into three main themes: concerns about the* aim *of continuous palliative sedation (27%), concerns related to the well-being of the* patient *(29%), and concerns related to the well-being of* relatives themselves *(18%). Patient and sedation characteristics did not differ significantly between sedations in which relatives did and did not express concerns, except for the duration of the sedation. The median duration of the continuous palliative sedation when concerns were expressed was 46 hours, compared with 19.5 hours when this was not the case* ($P < 0.05$). *Both the nature and extent of the concerns suggest that relatives are in need of continuous information and professional guidance during continuous palliative sedation of their family members. Availability of caregiver guidance and clear process documentation are crucial and indispensable in providing this.* J Pain Symptom Manage 2009;38:452–459.

Key Words
Palliative care, sedation, family, symptom control, palliative care unit

Introduction

By recommendation of the European Association for Palliative Care, palliative sedation is defined as the use of sedative medications to relieve intolerable and refractory suffering by a reduction in patient consciousness.[1] The aim of

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this sedation is to alleviate patient's suffering from refractory symptoms (i.e., severe symptoms for which treatment is no longer possible, or for which treatment will lead to unacceptable side effects). The most commonly reported refractory symptoms, and therefore, reasons for palliative sedation are terminal restlessness, dyspnea, and pain.[2–6] Following the subcategories proposed by Morita et al. (2001),[7] distinctions can be made in the degree and duration of sedation, and the pharmacological properties of the sedative. In the current study, all patients received primary continuous deep sedation.[7] More insight into the sedation characteristics in the patients in the current study is given in Rietjens et al.[6]

Professionals working in palliative care stress the importance of good care for the relatives of the patient, because they are the ones who are often present during the last period of the patient's life, and obviously, the most closely involved and concerned with the patient. The World Health Organization definition of palliative care incorporates providing a support system to help the family cope during the patient's illness and during their own bereavement.[8] The family is almost always involved in the decision-making process regarding palliative sedation. An extensive interview study among physicians in The Netherlands showed that the decision to use sedation was almost always discussed with the relatives of the patient (93%); in 25% of cases, the patient was considered incompetent or obtunded.[5] In the study by Rietjens et al. in the palliative care unit (PCU) at our cancer hospital, the decision to use sedation was discussed with relatives in 89% of the cases.[6]

With regard to experiences of relatives of patients who receive continuous deep palliative sedation, studies appear to be scarce. Morita et al. (2004)[9] studied the concerns and needs relatives had regarding continuous palliative sedation. In a study among 185 bereaved relatives on satisfaction and distress levels regarding palliative sedation in their family member, 78% expressed some level of satisfaction (ranging between slightly satisfied and completely satisfied). Twenty-five percent of the relatives reported that they had felt "very distressed" or "distressed" during the period of sedation. The relatives, however, were contacted a minimum of two years after the family member's death, which implies recall bias as a limitation of this study. The authors adopted this time frame on purpose, because of the possible emotional burden that would have been placed on the relatives in case of an earlier approach.[9] Another publication from the same study focused on the spontaneous comments that the relatives put in the questionnaire.[10] The relatives reported that they had experienced feelings of guilt, helplessness, and physical and emotional exhaustion during the dying phase. They had desired symptom relief for their family member, wished to communicate with the family member before sedation began, wanted to understand their family member's suffering, and wanted their family member to be treated with dignity. The authors concluded that clinicians need to be aware of these themes as being important for the relatives. They need to reassure the relatives and give sufficient information on the situation regarding the dying family member.

A qualitative study exploring nurses' experiences with palliative sedation in an American PCU and an American intensive care unit (ICU) reported that, next to the patient's suffering, the distress experienced by the family was a reason for the use of palliative sedation. Furthermore, palliative sedation was considered not only as a positive contribution to the patient's quality of dying but also as a positive contribution to the experience of the relatives; seeing their family member die while sedated offered them a sense of peace and closure after a difficult period of suffering.[11]

Information on the concerns and needs of relatives of patients who receive palliative sedation is of prominent importance to health care professionals. Based on more insight into the concerns of the relatives during the sedation process of their loved one, health care professionals can provide tailored information and support to the relatives during this difficult time in their lives. We aimed to explore and evaluate concerns of relatives *during* the use of continuous deep palliative sedation until death in their family member. An important advantage of our study is that the concerns were noted while the continuous deep palliative sedation was still ongoing, without recall bias. Furthermore, we explored if there were