Experiences of Family Members of Dying Patients Receiving Palliative Sedation

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Purpose/Objectives: To describe the experience of family members of patients receiving palliative sedation at the initiation of treatment and after the patient has died and to compare these experiences over time.

Design: Descriptive comparative study.

Setting: Oncology ward at Shaare Zedek Medical Center in Jerusalem, Israel.

Sample: A convenience sample of 34 family members of dying patients receiving palliative sedation.

Methods: A modified version of a questionnaire describing experiences of family members with palliative sedation was administered during palliative sedation and one to four months after the patient died. Descriptive statistics were used to describe the results of the questionnaire, and appropriate statistical analyses were conducted for comparisons over time.

Main Research Variables: Experiences of family members and time.

Findings: Most relatives were satisfied with the sedation and staff support. Palliative sedation was experienced as an ethical way to relieve suffering. However, one-third felt that it shortened the patient’s life. An explanation of the treatment was given less than half of the time and was usually given on the same day treatment was started. This explanation was given by physicians and nurses. Many felt that they were not ready for changes in the patient’s condition and wanted increased opportunities to discuss the treatment with oncology care providers. No statistically significant differences in experiences were found over time.

Conclusions: Relatives’ experiences of palliative sedation were generally positive and stable over time. Important experiences included timing of the initiation of sedation, timing and quality of explanations, and communication.

Implications for Nursing: Nurses should attempt to initiate discussions of the possible role of sedation in the event of refractory symptoms and follow through with continued discussions. The management of refractory symptoms at the end of life, the role of sedation, and communication skills associated with decision making related to palliative sedation should be a part of the core nursing curriculum. Nursing administrators in areas that use palliative sedation should enforce good nursing clinical practice as recommended by international practice guidelines, such as those of the European Association for Palliative Care.

Relieving suffering is one of the main aims of oncology care, particularly for dying patients (Bruce, Hendrix, & Gentry, 2006; World Health Organization, 2016). The suffering of a dying patient sometimes includes refractory symptoms. These symptoms are defined as severe symptoms—physical and psychological—that cannot be treated for long periods, or their treatment will lead to uncontrollable side effects (Schildmann & Schildmann, 2014). In most cases, treatment is focused on refractory physical symptoms, such as pain, dyspnea, and delirium (Schildmann & Schildmann, 2014), but psychological and existential suffering may also produce a