Brief Report

Palliative Sedation at Home for Terminally Ill Children With Cancer

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Abstract

Context. The presence of symptoms that are difficult to control always requires adjustment of treatment, and palliative sedation (PS) should be considered.

Objectives. We analyzed our experience in conducting PS at home for terminally ill children with cancer during a seven-year period.

Methods. We performed a retrospective analysis of medical records of children with cancer treated at home between the years 2005 and 2011.

Results. We analyzed the data of 42 cancer patients (18% of all patients); in 21 cases, PS was initiated (solid tumors $n = 11$, brain tumors [5], bone tumors [4], leukemia [1]). Sedation was introduced because of pain ($n = 13$), dyspnea (9), anxiety (5), or two of those symptoms (6). The main drug used for sedation was midazolam; all patients received morphine. There were no significant differences in the dose of morphine or midazolam depending on the patient's sex; age was correlated with an increase of midazolam dose ($R = 0.68$; $P = 0.005$). Duration of sedation ($R = 0.61$; $P = 0.003$) and its later initiation ($R = 0.43$; $P = 0.05$) were correlated with an increase of the morphine dose. All patients received adjuvant treatment; in patients who required a morphine dose increase, metoclopramide was used more often ($P = 0.0002$). Patients did not experience any adverse reactions. Later introduction of sedation was associated with a marginally higher number of intervention visits and a significantly higher number of planned visits ($R = 0.53$; $P = 0.013$).

Conclusion. Sedation may be safely used at home. It requires close monitoring and full cooperation between the family and hospice team. Because of the limited data on home PS in pediatric populations, further studies are needed. J Pain Symptom Manage 2014;48:968–974. © *2014 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

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Key Words
Palliative sedation, palliative care, children, home care, end of life

Introduction

According to the World Health Organization definition, palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial, and spiritual problems.[1] Despite the fact that palliative care is so multidimensional and multidirectional, all patients' symptoms will not always be controlled to a satisfactory degree. The presence of symptoms that are difficult to control in a given patient always requires adjustment of the applied treatment, and palliative sedation (PS) should be considered. The European Association for Palliative Care defines PS as controlled use of sedative drugs to limit consciousness, up to achieving unconsciousness, in a way that is ethically accepted by the patient, family and medical personnel.[2] Such therapy has been studied by many researchers worldwide, but in the developmental age population, it is highly controversial, both for medical professionals and society. In the available literature, there are very few reports on sedation in pediatric palliative care,[3–10] and scarce publications on home-based models of palliative care present only general principles of this procedure.[3,5,6,9] In Poland, palliative care for children has been mainly provided by specialized pediatric palliative home care teams and that home-based model of care is called "home hospice".[11,12] Home Hospice for Children of the Lodz Region (HHChLR) is a specialized pediatric palliative home care team and ranks third in Poland in terms of the number of treated children. In the Lodz Region (more than 2.5 million inhabitants with 471,000 children), there is only one other pediatric home hospice, and HHChLR looks after 90% of the children classified as needing palliative care. Usually, planned physicians' visits take place once a fortnight and planned nurses' visits twice a week. Patients have access to telephone consultation 24-hour a day, and intervention visits are always a response to the patient's health deterioration.

In this study, we analyzed our experience in conducting PS for terminally ill children with cancer treated by the HHChLR during a seven-year period. According to the authors' knowledge, this is the first report devoted to detailed PS procedures for children in the home setting.

Methods

We conducted a retrospective analysis of the medical records of children with a diagnosis of cancer treated by the HHChLR between January 2005 and December 2011. The following variables were abstracted from the medical records: 1) demographic information, 2) clinical information (principal diagnosis, detailed information about medications used for PS, indications for PS), and 3) follow-up information (time to death, duration of palliative care at home, duration of PS, the experience of the attending physician [specialist or resident], number of visits).

For the purposes of the present study, the following definitions were adopted: 1) PS is used as a last resort option to treat refractory symptoms in imminently dying patients; 2) a refractory symptom is one that cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness;[13] and 3) according to the World Health Organization definition, the authors describe adverse drug reaction as a response to a drug that is noxious and unintended and occurs at doses normally used in man for the prophylaxis, diagnosis, or therapy of disease, or for modification of physiological function.[14]

The study was approved by the Ethics Committee of the Medical University of Lodz (RNN/137/10/KE).

Statistical Analysis

Because of the limited number of samples and deviation from normal distribution of the analyzed variables, nonparametric tests were