

Original Article

End-of-Life Decision Making for Cancer Patients in Different Clinical Settings and the Impact of the LCP

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Abstract

Differences in the general focus of care among hospitals, nursing homes, and homes may affect the adequacy of end-of-life decision making for the dying. We studied end-of-life decision-making practices for cancer patients who died in each of these settings and assessed the impact of the Liverpool Care Pathway for the Dying Patient (LCP), a template for care in the dying phase. Physicians and relatives of 311 deceased cancer patients completed questionnaires. The LCP was introduced halfway through the study period. During the last three months of life, patients who died in hospital received anticancer therapy and medication to relieve symptoms more often than those in both other settings. During the last three days of life, patients who died in the hospital or nursing home received more medication than those who died at home. The LCP reduced the extent to which physicians used medication that might have hastened death. Relatives of patients who died in the hospital tended to be least positive about the patient's and their own participation in the decision making. We conclude that cancer patients who die in the hospital are more intensively treated during the last phase of life than those who die elsewhere. The LCP has an impact on the use of potentially life-shortening medication during the dying phase. Communication about medical decision making tends to be better in the nursing home and at home. J Pain Symptom Manage 2010;39:33–43. © 2010 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

End-of-life care, end-of-life decisions, decision making, palliative care, Liverpool Care Pathway for the Dying Patient

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Introduction

The goals of medical care need to be adjusted when death approaches. In the dying phase, the patient's comfort is key to all decisions about care and treatment.¹ Such decisions may involve the use of interventions aimed at symptom control and the forgoing

of burdensome or futile interventions. Symptom control and emotional support have been shown to be suboptimal for substantial proportions of patients dying in the hospital, the nursing home, or at home.^{2–8} The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments among bereaved relatives in the United States concluded that many patients dying in hospitals have unmet needs concerning symptom relief and psychosocial care.^{2,3}

In the World Health Organization definition of palliative care, both prolonging of life and hastening of death are stated not to be among the goals of care for the dying.¹ However, studies in several countries have shown that efforts to enhance the patient's comfort rarely result in the (possible) hastening of death.^{4,9} Such hastening of death is often an unintended effect of decisions to forgo potentially life-prolonging but burdensome treatment or to use highly dosed medication to relieve severe pain or other symptoms. In some cases, hastening of death is an appreciated or even explicitly intended effect because of the severe suffering of the patient without any prospect of relief.¹⁰

Decisions about medical care have to be made in all settings where patients die. The characteristics of each setting may have a significant impact on such decision making. Hospital care is primarily aimed at curing disease and prolonging life; death is usually an unforeseen outcome of hospital admission. Patients are typically admitted to a hospital for specialized, mostly short-term care, which cannot be given elsewhere. In the hospital, patients receive care from clinical specialists and hospital nurses. In The Netherlands, chronically ill patients who need constant care often are provided this in a nursing home. Death is often the expected final outcome of long-term admission to a nursing home. The nursing home physician and nurses provide nursing home care. Patients dying at home in The Netherlands usually receive care from their general practitioner with whom they often have a long-standing relationship and, if needed, from home care nurses who may visit the patients once or several times a day.

The Liverpool Care Pathway for the Dying Patient (LCP) has been developed to improve care for the dying in all settings. The LCP is

aimed at structuring care in the last days of life and at facilitating audit by standardizing the monitoring of care.^{11,12} It takes into account physical, psychosocial, and spiritual aspects and has been shown to improve patients' symptom burden and to contribute to the communication with patients and their families.¹³ One of the goals of care in the LCP concerns the decision making about which treatments are appropriate during the dying phase.¹⁴ The use of medication is assessed, and nonessential drugs are discontinued. Essential oral drugs are administered through the subcutaneous route, and a syringe driver is used if appropriate. PRN ("as required") subcutaneous medication is ordered for symptoms that may occur during the dying phase, such as pain and agitation. Medical and nursing interventions that are considered inappropriate, such as blood tests, intravenous fluids, or a routine turning regimen, are stopped.

We investigated physicians' and bereaved relatives' perspectives on end-of-life decision-making practices during the last three months and the last three days of life of cancer patients and assessed the impact of the LCP. We studied the three main settings for death and dying in The Netherlands, that is, the hospital, the nursing home, and the home.

Patients and Methods

Patients

Patients were recruited for our study in a university hospital (three medical oncology departments, a department for pulmonary diseases, and a gynecology department), a general hospital (a department of medical oncology), all departments in one nursing home (five general departments and one palliative care department), two departments in another nursing home (a general department and a palliative care department), a residential care organization that provides nursing care to about 60 people who live independently, and a home care organization that provides home care in a region of eight villages in the southwest of The Netherlands. The study comprised two consecutive periods: a baseline period, during which we assessed usual practices; and an intervention period, during which all departments used the LCP for patients who were recognized to be in

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