Original Article

Transitions of Care and Changes in Distressing Pain

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Abstract

This study employed a 22-state mortality follow-back survey to examine bereaved family members' perception of the level and pattern of distressing pain in decedents with cancer at the last two sites of care. Of the 1,578 individuals interviewed, 423 of their family members had cancer listed as the leading cause of death on the decedent's death certificate. Decedents were treated at home, hospitals, hospices, or nursing homes, with more than half of the respondents ($n = 216$) *reporting that the decedent was at more than one site of care in the last month. Forty-two percent of decedents had distressing pain (defined as "quite a bit" or "very much") at their second to last place of care, with 40% having distressing pain at the last place. There was some variation in the degree of change depending on the transition between the second to last and last places of care. For many individuals, however, the transition to another place of care did not result in an improvement in the level of distressing pain. No significant differences were found in the change in distressing pain by transition of care. Increased attention is needed not only on how to adequately manage pain and pain-related distress but also on how to improve pain reduction measures in transitions between health care settings at the end of life.* J Pain Symptom Manage 2006;32:104–109. *© 2006 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words

Pain, cancer, distress, transitions, place of care

Introduction

Advanced cancer will account for over 560,000 deaths in 2006.[1] For individuals with newly diagnosed and recurrent advanced cancer, cure is not possible. Instead, for these individuals, effective palliation—attempts to improve symptoms caused by the disease or associated treatments and maintain quality of life as long as possible—rather than cure is often the most appropriate goal of treatment. Recommendations from the Institute of Medicine and National Cancer Policy Board have stressed the need for an expanded role of palliation in the comprehensive management of cancer patients.[2]

For over 20 years, studies have documented that among the most common and distressing symptoms experienced by individuals with advanced cancer is pain.[3–5] A recent review

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of the literature revealed that the overall occurrence rates of pain are between 14% and 100%, with between 33%–50% of patients experiencing pain during the course of the diagnosis and treatment of cancer.[4] At the time of initial diagnosis, approximately 75%–80% of patients report pain,[6,7] with 10% of patients reporting severe pain.[8] In individuals with advanced cancer and those in palliative care settings, these rates are higher (70%–100%).[9,10] In three cross-sectional studies of advanced lung cancer,[11–13] uncontrolled pain was one of the most intense and common symptoms.

Pain can be the result of diagnostic or therapeutic procedures, side effects of treatment, or direct tumor involvement.[14,15] Although patients can be successfully treated for their pain with analgesics, many (42% of all cancer patients, and up to 59% of African American and 74% of Hispanic cancer patients) do not receive medication that is sufficient to manage the pain.[16] In some instances, individuals are not provided with the type of analgesic recommended by pain management guidelines, a problem that has been noted to occur more often in older minority women.[17] The result of inadequately controlled pain is increased distress that can severely reduce the quality of life during the last days of life.

Care for individuals with advanced cancer nearing the end of their lives may occur at home, a hospital, a nursing home, or a hospice. As previously noted, the goal of care during the last months of life is maintenance of quality of life and management of symptoms, particularly pain. Frequently, individuals are transitioned from one place of care to another in the last months or weeks of life. For example, for individuals treated in hospitals, the instituting of prospective payments has led to shorter hospital stays and quicker transitions to other settings. In addition, individuals may choose to die at home instead of in a nursing home or other health care setting.

At present, little is known about how the transitions that occur during the last months before death (e.g., from hospital to hospice or from home to hospital) affect pain in individuals with advanced cancer. Knowing the level of pain experienced by individuals before and after transition would help to determine whether pain improves, remains the same, or worsens with these transitions. In this study, we examined bereaved family members' perception of the level of distressing pain at the second to last place of care and last place of care through a 22-state mortality follow-back survey.

Methods

We conducted a mortality follow-back survey of deaths in 2000 in which we contacted the informant listed on the death certificate. Informants were usually a close family member or, when not, an individual who knew about the decedent's death and dying experience. The majority of interviews were conducted between 9 and 15 months after the patient died. The study design and informed consent procedures were reviewed by institutional review boards at Brown University, the University of Massachusetts, and within each participating state.

A two-stage probability sample included deliberate selection of eight states accounting for nearly 50% of deaths in the United States and random selection of 17 of the remaining 42 states. Deaths in sampled states accounted for 70% of total deaths in the United States in the year 2000. Complete interviews on 1578 informants represented 1.97 million deaths in the year 2000. For these analyses, we focused only on individuals for whom cancer was listed as the cause of death. Four hundred twenty-three (48% female, 9% African American, average age 72) informants had family members where cancer was listed as the leading cause of death on the death certificate. Based on national weights for the year 2000, these 423 cases were considered to represent 550,732 persons who died from cancer based on national weights for the year 2000.

Individuals were asked questions on the amount of pain ("During [the patient's] last days of life, how much of the time did [the patient] experience pain—not at all, occasionally, about half the time, most of the time, or all of the time?") and degree of distress from pain ("How much did the pain distress or bother [the patient]—not at all, a little bit, somewhat, quite a bit or very much?") experienced by the decedents at the last place of care and second to last place of care. The last place of care was defined as the location where the decedent spent at least 48 hours prior to his or her death. For these analyses, we excluded individuals who did not have a transition prior to their death.