Original Article

Hospice Caregivers' Experiences With Pain Management: "I'm Not a Doctor, and I Don't Know if I Helped Her Go Faster or Slower"

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Abstract

Context. Those caring for their loved ones in hospice experience tremendous stress, being faced with numerous decisions as they work to manage the pain experienced by their loved one. Although hospice care teams create pain management strategies, it is the role of the caregiver to implement these plans.

Objectives. The purpose of this study was to further understand the hospice caregiver experience relating to pain management.

Methods. Semistructured interviews with 146 caregivers provided data for the study. Responses to seven questions asking for a ranking of end-of-life pain management indicated a less than ideal experience. Available narratives from 38 caregivers were analyzed for themes related to further understanding of the concerns.

Results. Five themes were identified in the data including difficulty with administration of pain medicines, concerns about side effects of medications, insecurity with pain assessment, frustrations with communication among health care team members, and memories of unrelieved pain.

Conclusion. These findings should raise concern among hospice professionals, whose commitment is to the management of pain, including emotional pain, with a focus on both the patient and the family as a unit of care. These data clearly suggest that hospice providers have an opportunity to be sensitive to perceptions held by caregivers regarding pain management. Effective planning for pain control must incorporate the values and beliefs not only of each patient but also of the family caregiver. J Pain Symptom Manage 2013;46:846–858.

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Introduction

The prevalence of pain at the end of life and associated challenges with pain management are well documented. An Institute of Medicine[1] report suggests that 40% of those at the end of life have severe, unrelieved pain. Patients say barriers to effective pain management include communication problems with providers; structural problems in the health care system (difficulty obtaining medications); fears related to addiction; and personal attitudes, beliefs, and values.[2–4] Similarly, health care providers find patient adherence with pain medication regimens to be problematic.[5,6]

Hospice in the U.S. is largely a home-based service, and most care is provided in patients' homes by an informal, unpaid caregiver, often a family member of the dying patient. Nearly 70% of hospice deaths occur in the patient's place of residence.[7] Distressing pain and symptoms have been documented to affect 76%–90% of hospice patients.[8,9] The home of a dying patient has been compared with a hospital unit in which informal caregivers are expected to manage all aspects of patient care; those lacking formal education are left anxious, exhausted, and burdened.[10] Caregivers have been found to experience anxiety, depression, and physical symptoms.[11–15] Difficulty managing pain is significant, especially among older informal caregivers. The combination of dealing with the emotional distress from the expected loss of a loved one, the physical demands of caregiving, and the biological vulnerability brought on by age combine to increase the risk for their own health problems and early death.[16,17]

Pain is one of the most common and challenging symptoms to manage, especially when caring for a loved one. Research has shown that age, fears, beliefs, lack of assessment skills, burden, and strain are barriers to managing pain effectively.[18–23] Despite lack of training, informal caregivers must assess the severity of pain and make choices about how to administer medication to treat it. Hospice patients have complicated medication schedules, particularly regarding administration of opioids. It is a challenge for the caregiver to assess pain and bring into play "extra" opioid pain relief "as needed" (PRN) for "breakthrough" pain. It is often frightening to shoulder the responsibility of keeping a loved one comfortable by using a controlled medication.[24] And yet, hospice patients and staff alike rely heavily on informal caregivers to do just that. A confident, skilled, and trusting family member is often their best ally in preventing pain and implementing feasible management strategies.[25] Hospice teams spend as much as 38% of their time focusing on pain control during care planning meetings, yet typically do not include discussion about the challenges experienced by caregivers.[4]

Globally, support services in hospice and palliative care do not include programs aimed at training caregivers about pain management or systematic assessment of the caregivers' needs.[26,27] In some countries, death and dying remain taboo topics despite a preference for truth telling among patients and caregivers; thus, pain management is never discussed.[28] In Italy, for example, providers commonly provide diagnosis and prognosis information to the caregiver who then makes a decision about disclosure while simultaneously overseeing the management of care at the end of life.[29] Caregivers worldwide report a lack of psychosocial and emotional support while providing hospice and palliative care.[27,30] Less than 5% of all European caregivers have access to services aimed at addressing the psychological needs of caregivers; these services are particularly rare in Italy, Poland, and Greece.[26] In a U.K. study comparing inpatient hospice care to hospital care, bereaved relatives reported the hospice experience to provide better pain control and communication.[31]

Given the lack of caregiver support for pain management, the purpose of this study was to further understand the hospice caregiver experience relating to pain management. Specifically, the research questions guiding this study were: 1) How do hospice caregivers rate the experience with the pain management for their