Original Article

A Prospective Study of Family Conferences: Effects of Patient Presence on Emotional Expression and End-of-life Discussions

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Abstract

Context. Limited research has taken place examining family conferences (FCs) with patients with advanced cancer and their caregivers in the palliative care setting.

Objectives. To characterize the FCs involving cancer patients in a palliative care unit at a comprehensive cancer center and examine the effects of patient participation on emotional expression by the participants and end-of-life discussions.

Methods. A data collection sheet was completed immediately after 140 consecutive FCs that documented the number of participants, caregiver demographics, expressions of emotional distress, dissatisfaction with care, and the topics discussed. Patient demographics and discharge disposition also were collected.

Results. Seventy (50%) patients were female, 64 (46%) were white, and 127 (91%) had solid tumors. Median age of patients was 59 years. Patients participated in 68 of 140 FCs (49%). Primary caregivers ($n = 140$) were female (66%), white (49%), and the spouse/partner (59%). Patients verbalized distress frequently (73%). Primary caregivers' verbal expression of emotional distress was high (82%) but not significantly affected by patient presence (82% vs. 82%, $P = 0.936$). Verbal expressions of emotional distress by other family members were more common when patients were absent (87%) than when present (73%), $P = 0.037$. Questions concerning advance directives (21%), symptoms anticipated at death (31%), and caregiver well-being (29%) were infrequent. Patient presence was significantly associated with increased discussions regarding goals of care ($P = 0.009$) and decreased communication concerning prognosis ($P = 0.004$) and what symptoms dying patients may experience ($P < 0.001$).

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Conclusion. There was a high frequency of expression of emotional distress by patients and family members in FCs. Patient participation was significantly associated with decreased verbal emotional expression by family members but not the primary caregiver and was associated with fewer discussions regarding prognosis and what dying patients may experience. J Pain Symptom Manage 2013;46:536–545. *Published by Elsevier Inc. on behalf of U.S. Cancer Pain Relief Committee.*

Key Words
Palliative care, family conference, communication, end-of-life discussions, caregiver support

Introduction

Many family conferences (FCs) consist of structured meetings involving cancer patients and family members with the health care team (defined as physicians, nurses, social worker, case manager, and chaplain) in discussions concerning medical treatment, optimal symptom management, prognostication, advance directives, and plans for discharge into the community.[1]

The emotional transition from a curative to noncurative treatment and the shift from a hospital to a community setting elicit various degrees of psychological distress in both cancer patients and their families. The degree of distress experienced by the primary caregiver depends on multiple factors, including the level of understanding of options for cancer treatment and management of symptoms, the ability of the caregiver to cope with the transition from curative treatment to "comfort" care, and the family members' understanding of the role of hospice care.[2] Previous studies[3–5] reported increased feelings of helplessness among caregivers, which was associated with the progression of disease, the degree of struggle endured to obtain needed services, and the inability of caregivers to relieve the pain and discomfort of their loved ones.

The distress of patients and family members could be reduced by effective communication between clinicians, patients, and caregivers. Communication is a vital element in the provision of quality palliative care and when caregivers are well-informed, they are able to provide high-quality end-of-life care.[6] Inadequate communication can result in distress (stress, anxiety, and dissatisfaction[7]) because of the unmet information needs, lack of knowledge and understanding, lack of shared decision making, conflicts with staff and among family members, and lack of trust in the health care providers. Interventions such as the FC can facilitate communication with the caregivers of patients with advanced cancer by helping them understand the disease process and various options for treatment including management of symptoms at the end of life.

Limited research has taken place examining FCs with advanced cancer patients and their caregivers in the palliative care setting. A qualitative study of 24 videotaped FCs reported the emotional nature of the meetings and that participants valued being on the "same page" after the meetings.[8] At our institution, an initial retrospective review of 123 FCs in an inpatient palliative care unit (PCU) revealed a high degree of patient participation (60%).[9] Eighteen percent of patients expressed emotional distress, whereas 40% of the family members expressed distress that trended higher at 47% when patients did not participate in the meetings.[9]

The purpose of our study was to prospectively collect data examining the characteristics of FCs and describe the content of the discussions during the meetings. In addition, we wanted to examine both verbal and nonverbal displays of emotional distress by patients, their primary caregivers, and other family members. We hypothesized that patient presence during an FC affects the ability of the primary caregiver and other family members to freely express emotions and ask questions regarding end-of-life care.

Methods

Approval to conduct the study was obtained from the institutional review board before the