

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

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Reference: *Journal of Pain and Symptom Management* (March 2013), by Rony Dev, Luke Coulson, Egidio Del Fabbro, et al.

Abstract:

Background/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 to 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 were also 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 caregiver's verbal expression of emotional distress was high (82%) but not significantly affected by the 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 ($P < 0.001$).

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 the prognosis and what dying patients may experience.

Strengths/uniqueness: Studies in the ICU setting have shown improvements in the end-of-life communication, but limited research has taken place examining FCs with advanced cancer patients and their caregivers in the palliative care setting. This article suggests areas for further research such as the reasons for dissatisfaction with care in the palliative care unit, explore the concerns of patients and family regarding discharge.

Weakness: A major limitation of this study includes the lack of validated tools to collect information regarding FCs in the palliative care setting. Data collection was done by a single social worker immediately *after* the meetings were held. Inter-observer reliability was not determined with additional observers by video or audio play back.

Relevance to Palliative Care: Family conferences are a powerful clinical tool for communicating with patients and family members. There is a variable degree of information needs among patients at the end of life and their caregivers; therefore, patient presence in FCs is often determined on a case-by-case basis. Additionally, delirium and disease progression (such as brain metastasis) may affect the cognitive capacity of patients to actively participate in FCs.

