

Early Integrated Palliative Care and Reduced Emotional Distress in Cancer Caregivers: Reaching the “Hidden Patients”

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Disclosures of potential conflicts of interest may be found at the end of this article.

Given that family and friend caregivers of patients with advanced cancer are affected physically and emotionally by the patient's illness and are too often overlooked by health care systems, caregivers can be understood as “hidden patients” [1, 2]. Caregivers commonly take on new roles and responsibilities that can be physically and emotionally exhausting, while simultaneously grappling with emotional distress related to grief and future concerns. Accordingly, caregivers are at risk of depression and anxiety as well as reduced quality of life [3, 4]. Because the point prevalence of advanced cancer caregivers approximates 500,000 in the U.S. alone [5], this is a widespread public health concern. Given that early specialty palliative care integrated with oncology care has been shown to benefit quality of life and reduce depression for patients with advanced cancer [6, 7], a timely question is whether palliative care visits also help caregivers.

In this issue of *The Oncologist*, El-Jawahri et al. report on caregiver outcomes of a large randomized clinical trial of early integrated palliative care for patients with advanced lung or gastrointestinal cancer [8]. Relative to usual care, patients in the intervention group received monthly visits with a palliative care specialist emphasizing symptom management, coping, illness understanding, decision-making, and advance care planning. Although caregivers of patients in the intervention group were not required to attend the palliative care visits, they attended >70% of the time, with a median of 10 visits each. Findings showed that caregivers in the intervention group experienced less overall emotional distress, including depression and anxiety, especially closer to the patient's death. The magnitude of reduction in emotional distress (standardized mean difference of up to .30) was comparable to, if not greater than, what has been observed in several clinical trials examining patient outcomes of various models of palliative care [9]. Overall, these findings show that early integrated palliative care is not only beneficial for patients with advanced cancer but also worthwhile for reducing depression and anxiety in caregivers. This study provides empirical evidence reinforcing the American Society of Clinical Oncology's 2016 Clinical Practice Guidelines that all patients with advanced cancer and their caregivers should receive palliative care [10].

In weighing the medical evidence in support of early palliative care for patients with advanced cancer and their

caregivers, oncology clinicians should be keen to observe that this is among the most methodologically rigorous studies of palliative care. Several strengths stand out. One, the primary study [7] is the largest known clinical trial of ambulatory palliative care to date that randomized at the level of individual patients. Randomizing by patient, rather than clusters of sites or clinics, is challenging in this setting but important for ensuring balance across the study groups. Some of the large trials using cluster randomization had confounding that may have washed out salutary effects [11]. Two, the design of the study was “family-centered,” meaning that the intervention and outcomes were tailored in ways that will make the research more useful to patients and caregivers. For example, palliative care clinicians could tailor visit content to the unique needs of patients and caregivers. Additionally, caregivers attended most visits but were not mandated to attend when inconvenient, and caregivers are known to value the psychosocial outcome measures chosen for the study. Three, caregiver accrual was high, so results are unlikely to be affected by selection bias. Four, the study team brings a truly multidisciplinary perspective, spanning palliative medicine, oncology, internal medicine, nursing, psychology, psychiatry, and biostatistics. Surprisingly rare in studies of quality of care near the end of life, these diverse perspectives are vital for meeting the needs of the “whole” patient and caregiver [12].

This study [8] highlights the need for oncology clinicians to discuss the medical evidence for palliative care with patients, caregivers, and colleagues. Although most of the general public does not know what palliative care is, they fear it [13]. In a prior randomized study, explaining the medical evidence of early integrated palliative care led 75% of patients with cancer to experience more favorable attitudes toward palliative care [13]. Patients and caregivers who are reluctant to accept palliative care referrals may be encouraged to know that palliative care visits may benefit both parties; indeed, what people are scared to try themselves they are often willing to do for the benefit of a loved one [14]. Similarly, oncologists who are reluctant to refer patients to palliative care sometimes express that this would feel like giving up on or abandoning their patients [15]. Reimagining palliative care as service that can benefit the family unit may offset some oncologists' reluctance toward referral.

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As well, payers and hospital administrators who may have concerns about the cost-effectiveness of the development and expansion of palliative care programs should be particularly encouraged by these findings. Several models of palliative and psychosocial care [9, 16], especially the ENABLE III study [17], have been shown to benefit caregivers of patients with advanced cancer. Although extremely valuable, those models intervene with the caregiver separately from the patient. The early integrated palliative care model is innovative and potentially cost-effective because palliative care visits can benefit more than one individual simultaneously. Given that caregivers who experience the most intense and prolonged emotional suffering near the end of the patient's life are more vulnerable in subsequent years to mental health diagnoses, functional disability, and potentially mortality [18–20], the inclusion of family caregivers in palliative care visits could prove especially cost-effective in the long-term.

In summary, the El-Jawahri et al. [8] findings now demonstrate that the early integrated palliative care model is beneficial for reducing emotional distress in patients and caregivers. This large, methodologically rigorous clinical trial was innovative and expeditious in intervening with caregivers and patients simultaneously. Findings should be shared with patients, caregivers, colleagues, payers, and hospital administrators to increase utilization, development, and expansion of palliative care programs.

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Editor's Note:

See the related article, "Effects of Early Integrated Palliative Care on Caregivers of Patients with Lung and Gastrointestinal Cancer: A Randomized Clinical Trial," by Areej El-Jawahri et al. on page 1528 of this issue.