

# The Promise of Palliative Care

## Translating Clinical Trials to Clinical Care

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**In 1998, only 15% of US hospitals with 50 beds or more had a formal palliative care program; by 2013, the proportion had increased to 67%.<sup>1</sup>** Among larger hospitals (>300 beds),



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90% now have palliative care programs.<sup>1</sup> This expansion coincides with a growing body of high-quality evidence that supports the early involvement of palliative care specialists, even from the time a serious illness is initially diagnosed.<sup>2</sup>

Despite this growth in palliative care programs, **access to palliative care specialists remains limited for many people living with serious illness.** For example, patients with hematological malignancy are less likely to be referred to palliative care services than patients with solid cancers despite similar symptom burden and higher inpatient mortality.<sup>3</sup> When palliative care consultation does occur, it tends to happen much closer to the end of life. The reasons for this disparity are myriad, including the common misconception (held by both patients and clinicians) that palliative care equates only to end-of-life planning or hospice care, along with a lack of clinical trial data to support very early palliative care comanagement for patients who are still receiving potentially curative therapies.

In this issue of *JAMA*, El-Jawahri and colleagues present the results of a randomized trial that **provide the strongest evidence to date for integrating palliative care specialists throughout the duration of curative treatments for patients undergoing hematopoietic stem cell transplantation (HCT).**<sup>4</sup> This single-center clinical trial included 160 adults (mean age, 60.1 years) hospitalized for HCT. Individuals were randomly assigned to either a palliative care intervention that was integrated with transplant care (n = 81) or routine transplant care alone (n = 79). Patients in the intervention group were seen by palliative care clinicians at least twice per week during hospitalization, with the focus primarily on addressing physical and psychological symptoms. Patients assigned to usual care could be seen by palliative care on request.

**The primary outcome was change in patient quality of life (QOL)** measured by the Functional Assessment of Cancer Therapy–Bone Marrow Transplant (FACT-BMT) from baseline to week 2. Patients in the intervention group (assigned to palliative care) reported a smaller decrease in QOL from baseline to week 2 compared with patients in the control group (mean difference between groups in FACT-BMT score, –6.82; 95% CI, –13.48 to –0.16; *P* = .045). Among the key secondary outcomes, patients in the intervention group had less increase in depression, lower anxiety, and less increase in symp-

tom burden from baseline to week 2. At 3 months after HCT, patients in the palliative care group had higher QOL scores and less depression symptoms but no significant differences in anxiety, fatigue, or symptom burden. From baseline to week 2 after HCT, caregivers of patients in the intervention group compared with caregivers of patients in the control group had no significant differences in QOL or anxiety but did report lower increase in mean depression scores (0.25 vs 1.80; mean difference, 1.55; 95% CI, 0.14–2.96; *P* = .03).

The intervention used by El-Jawahri et al primarily addressed symptom management. Other core components of comprehensive palliative care consultation, including information sharing, eliciting goals of care, assisting with medical decision making, and advance care planning, were notably absent in the protocol. Perhaps integration of palliative care with standard transplant care necessitated a narrow focus because of the needs of patients and clinicians. However, placing the emphasis on symptom management can make palliative care more approachable, allowing time for relationship building among patients, caregivers, and the referring clinical service. By doing so, the palliative care team can more readily provide assistance in readdressing goals of care if a patient's condition deteriorates.

Studies such as that of El-Jawahri et al help define the broader clinical potential of palliative care, which remains a dynamic and evolving field. In particular, the results provide additional evidence that palliative care should not be restricted to the end of life. In contrast, many individuals with potentially curable disease could benefit from the integration of specialized palliative care teams into usual clinical care. The results also suggest that simply having palliative care consultation available is not sufficient; only 2 individuals in the control group received formal consultation despite a protocol that allowed patients, caregivers, or transplant clinicians to request palliative care involvement. The integration of specialized palliative care teams into usual clinical care should be adopted as part of an updated standard of care, similar to the routine involvement of pharmacy, nutrition, and social work.

**Interpreting the broader evidence base for palliative care is made more challenging because the interventions are not uniform,** unlike a medication that may have established routes, doses, and frequencies. Palliative care is multidimensional and varies in different clinical settings and from patient to patient. Furthermore, if viewed as a philosophy of care rather than a specific model of care, palliative care can be delivered by a range of individuals, from primary care clinicians to a formally trained, interdisciplinary team of subspecialists.

A second study in this issue of *JAMA* highlights the heterogeneity in palliative care delivery models and outcomes among published trials.<sup>5</sup> In a systematic review and meta-analysis, Kavalieratos et al reviewed 43 randomized clinical trials to determine the association of palliative care with potential benefits including QOL, symptom burden, and survival for individuals with life-limiting illness and their caregivers. The inclusion criteria in the report by Kavalieratos et al were broad and not limited to interventions delivered by palliative care specialists. The 43 randomized clinical trials included data on 12 731 patients (mean age, 67 years) and 2479 caregivers. The authors reported that compared with usual care, palliative care interventions were associated with improved patient outcomes at 1- to 3-month follow-up, including clinically significant improvements in patient QOL (standardized mean difference, 0.46; 95% CI, 0.08-0.83; mean difference, 11.36 on the Functional Assessment of Chronic Illness Therapy-Palliative Care subscale, with 9 points considered a clinically important difference) and symptom burden (standardized mean difference, -0.66; 95% CI, -1.25 to -0.07; mean difference, -10.3 points on the Edmonton Symptom Assessment Scale [range, 0-90 for best-worst], with 5.7 points considered a clinically important difference). There was no association between palliative care and survival, and results were less consistent for caregivers.

The negative trials included in the analysis by Kavalieratos et al should not be overlooked; these are equally as important as the positive studies and help define the boundaries of palliative care, specifically what approaches may be most effective among a rapidly expanding body of palliative interven-

tions. For example, another recently published multicenter randomized trial examined palliative care clinician-led informational support meetings for 256 patients with chronic critical illness and 365 family surrogate decision makers; the results found no improvement in anxiety or depression symptoms among family surrogate decision makers at 3 months.<sup>6</sup> Just as the trial by El-Jawahri et al defines the possible, this study provides a cautionary tale that care delivered by specialists may not be effective when following a highly structured study protocol that solely aims to provide informational support with little regard to what makes this process meaningful to many patients, families, and clinicians: frequent and longitudinal follow-up, close involvement with the primary clinical team, and a focus on relief of physical and psychosocial distress.

Along with a growing list of studies demonstrating benefit of palliative care, there is an imperative to train both specialists and nonspecialists to deliver interventions proven to be effective. A multipronged approach, such as the Palliative Care and Hospice Education and Training Act (PCHETA),<sup>7</sup> provides a road map for how to accomplish this goal. Along with expanding palliative care research and public awareness, PCHETA is designed to establish a nationwide network of palliative care and hospice education centers that could expand specialist training programs and also train all clinicians in providing high-quality palliative care. With estimated expenditures of up to \$49.1 million per year,<sup>7</sup> the cost of PCHETA is small compared with the potential benefits of meaningfully improving the quality of life of individuals living with serious illness.

#### ARTICLE INFORMATION

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