

Palliative Care for Patients With Noncancer Illnesses

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The term palliative care was coined in 1975 to describe the core goals of a newly created hospital-based service in Quebec, Canada, designed to improve quality of life and mitigate sources of distress for patients with serious life-threatening illness.¹ Now, 45 years later, palliative care retains its central focus on improving quality of life for individuals with serious life-limiting illnesses and their families by addressing physical and psychological symptoms and social and spiritual needs and aligning patient and family values with available care options.



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To date, the evidence for the benefits of palliative care among patients with cancer is far more advanced than the evidence for patients with serious noncancer illnesses. In a 2016 systematic review and meta-analysis of 43 randomized clinical trials (RCTs) of specialty palliative care, 70% of the trials included patients with cancer.² Yet, cancer represents only a fraction of serious illness,³ and the needs of patients with cancer are often distinct from those of patients with serious noncancer illness.⁴ Patients with advanced heart disease or lung disease often have a less predictable course punctuated by periods of exacerbation, decline, and remittance.⁴ Consequently, a key question remains: can the benefits of palliative care demonstrated among patients with cancer be translated to other disease groups and patient populations?

In this issue of *JAMA*, Quinn et al⁵ report findings from a systematic review and meta-analysis of RCTs of palliative care interventions for people with noncancer chronic illnesses. The authors developed and used a broad definition of a “palliative care intervention,” which involved at least 2 or more of the 8 domains defined in the 2018 National Consensus Project Clinical Practice Guidelines for Quality Palliative Care,⁶ to assess both specialist and generalist models of palliative care compared with usual care. The study included 28 RCTs published between 1985 and 2019 that reported findings on 1 or more of 3 primary outcomes of interest. All studies were comprehensively assessed for risk of bias. In their meta-analysis, the authors examined the primary outcomes of hospitalizations, emergency department (ED) use, quality of life, and symptoms; a secondary outcome of advance care planning was added after reviewing the data of included trials.

The diversity of identified studies and their combined findings suggest palliative care provides benefits for patients with noncancer illness. Palliative care interventions, compared with usual care, were associated with less ED use (9 trials pooled for meta-analysis [n = 2712 patients]; 20% vs 24% of patients with ED use; odds ratio [OR], 0.82 [95% CI, 0.68-1.00]) and hospitalizations (14 trials [n = 3706 patients]; 38% vs 42% of patients; OR, 0.80 [95% CI, 0.65-0.99]) and lower symptom burden (11 trials [n = 2598 patients]; pooled standardized mean difference [SMD], -0.12 [95% CI, -0.20 to -0.03]). Compared with usual care, more

patients who received palliative care received advance care planning (7 trials [n = 5935 patients]; 38% vs 42%; OR, 2.95 [95% CI, 1.52-5.73]). Avoiding potentially burdensome health care use, mitigating distressing symptoms, and engaging in advance care planning⁷ are conceptually critical to the goal of palliative care of improving quality of life for patients. However, unexpectedly, palliative care interventions were not associated with significant improvement in quality of life as measured by disease-generic quality of life scales (6 trials [n = 1334 patients]; SMD, 0.18 [95% CI, -0.24 to 0.61]) or disease-specific scales (11 trials [n = 2204 patients]; SMD, 0.07 [95% CI, -0.09 to 0.23]).

The findings in the study by Quinn et al⁵ provide important data about the clinical benefits of palliative care in patients with noncancer illnesses. A key question that emerges from the findings is why were interventions devoted to quality of life seemingly not associated with better quality of life? There are several potential explanations.

First, as the authors acknowledge, there was substantial heterogeneity in what constituted a “palliative care” intervention in the RCTs included in the analysis. Quinn et al⁵ cast a wide net by using minimum criteria of at least 2 of 8 domains from the 2018 National Consensus Project Clinical Practice Guidelines for Quality Palliative Care.⁶ Certain interventions did not self-identify as “palliative care,” but were framed as complex care management or post-hospital discharge care.^{8,9} Such interventions, such as in the study by Van Spall et al,⁸ would not be viewed as complete palliative care interventions by palliative care experts. A complete palliative care intervention would include all 8 domains, an interdisciplinary team, and clinicians with specialty training in palliative care. In analyses that were limited to interventions in which palliative care physicians or interdisciplinary teams were present, there were clinically meaningful improvements in quality of life scale scores. Interdisciplinary care teams may contribute to improving patients’ quality of life by focusing on spiritual, social, or cultural domains that are often ignored. Involvement of a physician or an interdisciplinary team may be essential for coordinating longitudinal services.¹⁰ Findings might be interpreted as indicators of the “dose response” of training, expertise, and provision of palliative care. Further research and consensus are needed to define the minimum dose that makes an intervention palliative care.

Second, the trials included in the study by Quinn et al⁵ were conducted in a variety of settings. Patients in hospital inpatient settings, outpatient clinics, nursing facilities, or residential homes have different needs and are often in different stages of illness.¹¹ Combining these various settings and patient populations in a single review and meta-analysis may dilute the effect of setting-specific interventions. The authors examined the magnitude of association between intervention and outcomes

for trials that used home-based palliative care, but did not conduct other setting-specific analyses.

Third, the mechanisms by which symptoms and other sources of distress arise are often disease specific. Advanced heart failure and dementia differ in prognosis, symptoms, and caregiver needs. Moreover, the quality of evidence for symptomatic treatments varies substantially by disease. The evidence base for management of cancer pain is far more extensive than the evidence for interventions that target symptoms common in noncancer illness, such as breathlessness, fatigue, and depression.

Heterogeneity across these domains raises a fundamental question: should these disparate models, settings, and diseases be combined in a single systematic review and meta-analysis? Although the maturity of the evidence base for noncancer palliative care varies widely across these domains, the authors rightly suggest that their review provides a roadmap for the future study of palliative care and note that their findings provide support for health systems to continue to expand palliative care to patients with noncancer illness. Addressing major gaps in the palliative care evidence base identified in this review requires systematic change.

Although nearly everyone will develop a serious illness at some point in their life, awards for palliative care research represent less than 1% of the grants awarded by the National Institutes of Health (NIH).¹² Between 2001 and 2015, 80% of awards for palliative care research were funded by 3 NIH institutes: the National Cancer Institute, the National Institute for Nursing Research, and the National Institute on Aging.¹² In contrast, the National Heart, Lung, and Blood Institute funded 2.5% and the National Institute on Diabetes and Digestive and Kidney Dis-

eases funded 0.5% of NIH grants for palliative care research.¹² Quinn et al noted a paucity of RCTs of palliative care for several common serious illnesses, including chronic obstructive pulmonary disease, kidney failure, stroke, and cirrhosis. Without investments by funders, it will be challenging to develop the relevant evidence base for these conditions.

In addition, more investigators are needed to conduct palliative care research, including those who specialize in palliative care and those who specialize in the diseases or conditions of focus. The decades-long oncology-palliative care partnership provides a model for collaboration and innovation. Moreover, there are insufficient numbers of palliative care physicians to meet the needs of patients living with serious illness,¹³ suggesting that the number of specialist-trained palliative care clinicians needs to increase and that all clinicians should receive training in basic palliative care principles to meet the current and inevitable impending increase in palliative care needs as the population ages. Furthermore, future trials should combine the expertise of multiple disciplines; for instance, effective palliative care for patients with dementia may need to involve clinicians with expertise in geriatrics, geriatric psychiatry, and behavioral neurology to improve quality of life for patients and caregivers.

The findings of Quinn et al⁵ reported in this issue of *JAMA* provide evidence that palliative care is associated with reduced acute care service use, mitigation of symptoms, and increased advance care planning in patients with noncancer illnesses. The review also underscores the need to fund, develop, and test interventions that provide relief of symptoms, interventions that improve quality of life, and interventions for diseases for which little or no randomized trial-level evidence currently exists.

ARTICLE INFORMATION

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