



Stepped palliative care: considerations for equitable implementation

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Palliative care aims to enhance the quality of life (QOL) for patients and their families facing the challenges associated with serious, often terminal illness, and it seeks to incorporate patients' physical, psychological, and spiritual needs. The benefits of palliative care have been long established, with numerous studies demonstrating improvements in pain and symptom control, reduced anxiety, enhanced QOL, and reduced hospital admissions (1). Early palliative care, in which palliative care is initiated at the time of diagnosis or upon recognition of limited life expectancy—has become an important standard for patients suffering with advanced cancers. Initiation of early palliative care can reduce unnecessary aggressive care at the end of life and even significantly prolong survival in patients with advanced malignancies (2,3).

However, achieving equity in palliative care delivery has been hindered by lack of resources, equipment, financing, qualified staff, and organizational barriers, especially in lower-resourced community settings (4-6). Even in the presence of adequate financial and organizational resources, cultural beliefs, communication challenges, and inadequate insurance coverage further limit palliative care delivery to some patients. Every year, only half of the over 2 million beneficiaries enrolled in the United States federal health insurance program Medicare are enrolled in hospice before

the time of their death. These challenges are exacerbated for vulnerable populations, particularly rural, tribal, and undocumented patients who face additional barriers such as geographic isolation, lack of access to culturally competent care, and fear of seeking services due to their immigration status, respectively (7-10). Additionally, inequities in palliative care delivery continue to persist along racial/ethnic lines (10): patients receiving care in minority-serving hospitals are only 67% as likely to receive palliative care, with 20% of Black and 16% of Hispanic patients receiving palliative care compared to 23% of non-Hispanic white patients (11). As a result of these systemic barriers, recent efforts have focused on innovative, more patient-centered, and less resource-intensive approaches to delivering high-quality palliative care. In this editorial commentary, we propose equitable considerations for palliative care delivery to under-served racial/ethnic groups, while recognizing the importance of equitable implementation for other marginalized groups based on age, residence location and sexual orientation and/or gender identification, emphasizing the promise of stepped palliative care in achieving this goal in under-served racial/ethnic groups.

Stepped palliative care, a resource-efficient approach, is emerging as a promising delivery method that Temel *et al.* recently reported in *JAMA* to be noninferior to traditional

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early palliative care approaches (12). Stepped palliative care involves minimal initial clinician contact, escalating to intensive palliative care exposure if needed based on systematic monitoring. In this large randomized non-blinded clinical trial of 507 adult patients with advanced lung cancer (Eastern Cooperative Oncology Group performance status of 0 to 2) across three hospitals across three states in the United States, Temel *et al.* compared patient-reported QOL through the Functional Assessment of Cancer Therapy-Lung (FACT-L) questionnaire as the primary outcome. Secondary endpoints included palliative care utilization (measured through number of visits), patient-reported communication about end-of-life care preferences, and length of hospice stay. Exploratory endpoints included depression symptoms through the Patient Health Questionnaire-9 (PHQ-9) and coping skills through the Coping Orientation to Problems Experienced Inventory (Brief-COPE) questionnaire. The study found no significant differences in quality-of-life scores, communication about end-of-life preferences, depression symptoms, or coping skills between patients receiving stepped versus early palliative care. Notably, stepped palliative care reduced the number of palliative care visits by half compared to early palliative care, where patients were scheduled for palliative care visits every 4 weeks, independent of a patient's needs.

By tailoring palliative care delivery to each patient's care needs, including QOL needs and illness trajectory, Temel *et al.* demonstrated that stepped palliative care provides a promising, resource-efficient alternative to traditional early palliative care methods. Fewer required visits may alleviate the significant issue of palliative care workforce shortages, which remains a major barrier to palliative care delivery (13). Simultaneously, stepped palliative care does not compromise on the patient-centered nature of care, while still ensuring patients achieve comparable QOL, mental health benefits, and coping skills. Especially for hospitals with limited capacity to ubiquitously implement early palliative care or for patients with a terminal prognosis but extended expected survival, integration of stepped palliative care can optimize resource use and maintain high standards of patient care, making it a viable and effective option in diverse healthcare settings.

However, the current stepped palliative care approach will need to continue to evolve in directions that emphasize equitable care delivery. Notably, the patient population in Temel *et al.* consisted predominantly of patients who were white, Christian, or married or partnered. As such, further

research investigating the impacts of stepped palliative care in diverse racial/ethnic and minority communities is warranted. Additionally, a framework relying heavily or solely on illness-specific metrics or QOL metrics may not be adequate for diverse communities with unique needs. Additionally, the provision of culturally competent services must be at the forefront of stepped palliative care delivery, especially if implemented in minority-serving hospitals with limited resource (10). As the findings by Temel can allow for the ability to expand access to palliative care through the less resource-intensive stepped approach, we must ensure that population-specific research and systematic monitoring identifies and addresses all patient needs, and that care is delivered through culturally competent channels.

First, given the heavy reliance on changing conditions to adjust the palliative care delivery routine, special consideration must be given to ensure robust monitoring based on a carefully curated set of assessment metrics. Temel *et al.* used a 10-point decrease in QOL scores based on the FACT-L questionnaire as the metric for patients to be “stepped up” to more intensive palliative care visits. While measures of QOL are an appropriate starting point for implementing stepped palliative care, this method to determine care intensification could benefit from refinements, such as the use of more granular assessments, to prevent unmet patient needs. Defining and acting upon actionable metrics—such as patient-reported pain levels, emotional or psychological needs, spiritual and existential concerns, physical symptoms, and family and caregiver needs for support—can identify patients who may require more intensive, issue-specific palliative care sessions (14). By refining these assessment strategies, we can ensure that stepped palliative care remains responsive and adaptive to the evolving needs of patients.

Second, the method of QOL questionnaire delivery must be carefully honed to prevent the exacerbation of health disparities. Studies have shown that certain social determinants of health may affect differential survey completion rates. One study found that women, younger adults, Hispanic and Black adults, and people with less formal education were less likely to answer open-ended survey questions, which may translate to differential non-response rates when administering FACT-L questionnaires for stepped palliative care (15). As such, it may be beneficial to administer FACT-L questionnaires or other such surveys of assessment metrics directly within a clinical consultation to avoid exacerbating health disparities associated with differential non-response, especially as stepped palliative

care is upscaled to communities with higher proportions of under-served populations.

Given the importance of clinical consultations in stepped palliative care, we must incorporate culturally tailored care delivery tactics to augment the patient-centered experience. For instance, family-oriented care is very prominent in some Asian cultures, in which healthcare decisions are deliberated extensively with the family, sometimes manifesting in the patient preferring less information delivered directly to them in lieu of family-led decision-making (16). Additionally, studies have documented the tendency for more aggressive and non-beneficial end-of-life care to be delivered to Black patients coupled with less transparency about health-related information provided to Black patients (17). A degree of medical mistrust may be more common among Black patients due to historical and present inequities (18), contributing to lower uses of hospice care (17). In a system where palliative care resources differ among patients, such as with stepped palliative care, failure to acknowledge cultural determinants of palliative care receipt and failure to tailor interventions accordingly may introduce implicit bias that can exacerbate an area already rife with disparity, leading to suboptimal outcomes along racial/ethnic and/or cultural lines (10). For communities that prefer a family-centric care model, greater incorporation of family members or trusted community messengers may provide patients with a more comfortable and values-concordant care experience. For all diverse communities, thorough training of staff on unique cultural considerations of certain racial/ethnic, immigrant, low-income, or other vulnerable populations is crucial. Such considerations are especially relevant for stepped palliative care, as fewer visits amplify the need for culturally competent care to ensure that every interaction is impactful and meets the diverse needs of patients.

Temel *et al.* should be commended for demonstrating a remarkably innovative approach to future palliative care delivery that is particularly promising for limited-resource hospitals serving diverse patient populations. While the stepped palliative care approach is an encouraging first step showing noninferiority compared to uniform early palliative care, considerations such as more granular assessment metrics and culturally tailored care delivery are especially pertinent for diverse patient populations with nontraditional care needs. Moving forward, integrating these refinements into stepped palliative care protocols could enhance the effectiveness and inclusivity of care delivery, ensuring that all patients receive the highest quality of palliative care tailored to their unique needs.

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