

EDITORIAL AND COMMENT

The Importance of a Comprehensive, Patient-Centered Approach to End-of-Life Care

Anne M. Walling, MD, PhD^{1,2} and Sydney M. Dy, MD, MSc^{3,4}

¹Division of General Internal Medicine and Health Services Research, David Geffen School of Medicine at University of California, Los Angeles, CA, USA; ²Greater Los Angeles Veterans Affairs Healthcare System, Los Angeles, CA, USA; ³Department of Health Policy & Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA; ⁴Harry J. Duffey Family Pain and Palliative Care Program, Johns Hopkins Kimmel Cancer Center, Baltimore, MD, USA.

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Relieving suffering of the dying patient is a core mission not only of palliative care providers, but of every clinician who participates in the care of seriously ill patients. Too often, patients and families suffer unnecessarily at the end of life because dying is not recognized, providers do not communicate about prognosis, and symptom management is inadequate. Several studies have documented unmet needs related to communication and symptom management for patients who die in the hospital in the United States.^{1,2} This problem is multi-factorial. Despite the fact that early advance care planning discussions are associated with better patient and caregiver outcomes,^{3,4} studies suggest that these discussions are often delayed⁵ and quality measures in this domain are often not met.^{6,7} There is, instead, a tendency to focus on disease-focused rather than patient-centered treatments, which often leads to patients receiving care inconsistent with preferences or prognosis.

Even when patients are identified to be at the end of life, they are often not treated using accepted standards for end-of-life care.⁸ This may be due to multiple issues, including continued invasive medical interventions, lack of knowledge about evidence-based comfort care approaches, and adverse attitudes toward and lack of knowledge about use of opioid medications at the end of life. The multi-site study by Bailey and colleagues in this issue of JGIM⁹ has important implications for how to improve care provided to hospitalized patients at the end of life. It also highlights the importance of implementation science in the study of quality improvement interventions, which are challenging to evaluate with randomized controlled trials and often require customization to local environments in different health care settings. With a detailed, multi-pronged approach based on a successful single-institution pilot study including staff education, palliative care team involvement, an electronic medical record-based comfort order set, and

adjustments in pharmacy and nursing policy, the study team was able to successfully change clinician behavior so that patients were more likely to have treatments available for distressful symptoms such as pain and delirium. There were also significant decreases in the rate of nasogastric tube use and increases in advance directive use and sublingual administration of medications.

It is important to note that there was not a statistically significant change in receipt of opioid medications at the end of life and more than a third of patients did not receive opioids at the end of life, despite this intensive intervention. Whether this is due to lack of need is unknown, but a recent qualitative study of this intervention provides insights into the importance of the structural components of quality (i.e. ensuring hospital policies support best practices)¹⁰ and how delays in implementation of updated policies and staff turnover may have limited the dose response for this intervention. This related qualitative work can be used to improve future implementation of this intervention, and is an example of the importance of mixed methods in implementation science. In addition, other studies of quality improvement interventions have found that it can be challenging to significantly impact multi-step processes that require addressing multiple barriers; i.e., ordering a medication requires only one step, whereas increasing the rate of medication administration requires at least two.

A potential strength of the intervention is that the comfort care orders were designed so that they could be used concurrently with disease-directed treatment, which could have increased use of the order set and made it available to more patients, but could also have muted the effect of the intervention in some cases. Concurrent treatments are often required to achieve optimal symptom control, such as the continuation of furosemide and other cardiac medications in patients with heart failure. This may have also been a potential limitation, as encouraging discontinuation of more intensive disease-directed treatment (such as invasive procedures or highly emetic chemotherapy) can be an important factor in reducing patient suffering. Nonetheless, the emphasis in this study on individualizing patient care plans with the support of an order set, rather than transitioning patients to a standard comfort-only plan, is important.

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This study also demonstrates how difficult it is to measure and improve quality of care at the very end of life—but that it can and should be done. Structural aspects of care, such as the introduction of a policy for administration of sublingual medications, were a required step for success of the intervention, and led to measurable improvements in processes of care, such as the receipt of sublingual medications in dying patients. Even more challenging is to determine the impact of this type of intervention on patient outcomes. Every death is different and they do not always follow an expected course. The overall goal is to ensure that a patient's death aligns with patient and family preferences, and that unmet needs for communication and symptom management are addressed. Outcomes are therefore individualized and a moving target, making measurement difficult. Although the goal of the study was not to evaluate outcomes, given that the Veterans Administration has recently implemented a national program to measure patient and family experience for end of life care, the VA and this team of investigators might be in a unique position to explore this question in future work.¹¹

Prior single site studies implementing end-of-life order sets have suggested improvement in the rates of use of palliative medications at the end of life,^{12,13} but a recent Cochrane review indicated that there was not enough evidence to make a recommendation for or against the use of end-of-life care pathways.¹⁴ This study shows that implementing an end-of-life order set or pathway is just one part of an implementation strategy needed to improve care for patients at the end of life. The multimodal nature of the intervention (in addition to an electronic order set) included extensive education and involvement by local multidisciplinary palliative care teams, as well as a concomitant emphasis on communication with families. An electronic order set without proper training, oversight or tailoring could lead to unintended consequences, such as use without adequate review or family communication, which is why this study is such an important model. The study also demonstrates the importance of having local palliative care clinicians available to aid in implementation. In a recent systematic review of quality improvement interventions in palliative care, we found that interventions that included this consultative approach were more likely to be successful than those that depended solely on education, training, and structural change for the existing clinicians.¹⁵

There is a critical need for research that addresses the challenges of translating interventions that work well in one setting to others more broadly, and evaluating customization and implementation across different contexts. This study is an important step for improving care for patients as they approach the end of life, but more is needed to ensure that patients are receiving indicated interventions and that comfort is achieved in appropriate dying patients. Inpatient-based interventions such as these should be more widely implemented and evaluated in concert with measurement of the quality of care.

They should also be coupled with other interventions across venues of care to encourage early advance care planning and improve the likelihood that a patient's elicited goals and preferences guide his or her overall treatment plan, and that comfort-oriented measures are implemented in a timely manner when indicated.

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Corresponding Author: Sydney M. Dy, MD, MSc; Rm 609, 624 N Broadway, Baltimore, MD 21205, USA (e-mail: sdy@jhsph.edu).

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