Unmet Quality Indicators for Metastatic Cancer Patients Admitted to Intensive Care Unit in the Last Two Weeks of Life

Jennifer A. Blechman, MD,¹ Norman Rizk, MD,¹ Marguerite M. Stevens, PhD,²
and Vyjeyanthi S. Periyakoil, MD^{1,3}

Abstract

Background: The majority of U.S. cancer patients express the desire to die at home, though most do not, and are often subjected to ineffective therapies near the end of life (EOL). In 2008 the U.K. Department of Health and National Health Care Service implemented a set of 10 quality markers to improve EOL care (EOLC) for seriously ill persons. Data show that this intervention has had a positive impact on patients' EOLC.

Purpose: The study assessed the quality of EOLC received by terminally ill cancer patients admitted to the intensive care unit (ICU) in the last two weeks of life.

Design: A retrospective chart review was done of the electronic medical record (EMR) of 2498 patients admitted to the ICU from January to August 2011. The six U.K. quality indicators pertaining to patients were used to assess quality of EOLC.

Setting: The setting was a tertiary academic medical center with 663 beds and 66 adult ICU beds in northern California.

Patients: EMR analysis identified 2498 patients admitted to the ICU during the study period—232 died within two weeks of admission. Sixty-nine decedents had metastatic cancer. Of the patients, 58% were male, average age 59.8 years (range 25–91).

Results: Quality indicators were met in a relatively small percentage of patients admitted to the ICU in the last two weeks of life: prognostication 67%, advance care planning 32%, goals of care 42%, caregiver needs 0%, coordination of care across organizational boundaries 7%, and standardized care pathway implementation 58%. Palliative care consultations occurred in 28 patients.

Conclusions: Quality indicators for EOLC were unmet in cancer patients admitted to the ICU in the last two weeks of life. Hospital-wide provider education about the need for early advance care planning with all seriously ill patients has been implemented in an effort to improve quality of care at EOL.

Introduction

OVER 90% OF ADULTS in the United States state that they would prefer to die at home,¹ including 50%–93% of cancer patients,^{2–4} though fewer than 25% of deaths occur at home.⁵ Many patients who are dying expected deaths due to terminal illnesses are needlessly hospitalized, subjected to ineffective treatment interventions that erode their quality of life, and often die in the hospital with numerous distressing symptoms. Though the majority of U.S. hospitals with >300 beds have palliative care services,⁶ many seriously ill patients still do not have early access to palliative care, or consults occur just proximal to death, thus allowing insufficient time to implement effective symptom palliation and patient-congruent care.

In 2008 the United Kingdom implemented a nationwide 10-year plan to improve end-of-life care (EOLC).⁷ Accordingly, they established a set of markers for quality at the end of life (EOL), with the goal to “help people with advanced, progressive, and incurable illnesses to live as well as possible until they die.”⁸ This effort has been very successful, applied to over 7000 patients, with evidence that the needs of dying patients have become more prominent in clinical practice.⁹

Our study was undertaken to examine the quality of EOLC of hospitalized metastatic cancer patients admitted to the intensive care unit (ICU) in the last two weeks of life in an academic medical center using the U.K. quality indicators. The 10 U.K. EOLC quality indicators⁷ were examined, and 6 of the 10 were noted to pertain to patient-specific issues, while 4

¹Stanford University School of Medicine, Palo Alto, California.

²Dartmouth University School of Medicine, Hanover, New Hampshire.

³VA Palo Alto Health Care Systems, Palo Alto, California.

Accepted May 28, 2013.

were system-specific measures. We utilized the 6 patient-specific measures (see Table 1) to assess the quality of EOLC. All aspects of this study were reviewed and approved by the Stanford University institutional review board.

Methods

This was a retrospective chart review study of electronic medical records (EMR) of all ICU admissions to identify metastatic cancer patients in the ICU in the last two weeks of life.

Patients

All patients admitted to Stanford Hospital ICU from January through August 2011 were included in the study. EMR review identified a total of 2498 patients who were admitted to the ICU. Cross-referencing each patient's date of ICU admission to the date of death identified 232 patients who were admitted to the ICU in the last two weeks of life. For each subject, detailed chart review was undertaken of all aspects of the EMR including but not limited to admission notes, progress notes, subspecialty consult notes, discharge summaries, automated order sets, and advance care planning; and care provided in the last six months of life was evaluated, from records of inpatient, outpatient, outside hospitals/providers, emergency room, and advance directives/Physician Orders for Life-Sustaining Treatment (POLST) forms.¹¹ The analyses had three focuses:

1. Whether the six U.K. quality indicators were met for each subject, as documented in the EMR.
2. Whether each subject had received palliative care consultation.
3. Whether there was any relation between the palliative care consult and the fulfillment of the six quality indicators.

Results

Of the 2498 ICU admissions, 232 patients had been admitted to the ICU in the last two weeks of life, 86 had an International Classification of Diseases (ICD) diagnosis code¹⁰ of metastatic cancer, and in 69 patients cancer was the primary cause of death. The results for each of the six quality markers are as follows (see Fig. 1):

Assessment and documentation of prognostication

Of the 69 cancer patients admitted to the ICU in the last two weeks of life during the study period, 46 patients (67%) had some notation of prognostication, either the Eastern Cooperative Oncology Group (ECOG) or the Karnofsky Performance Status (KPS) performance scales.¹² Only 7 of the 46 cases had specific documentation that prognosis was discussed with the patient and used as a rationale for appropriately implementing or withholding disease directed therapies.

Documentation of advance directives in the EMR

Of the 69 patients with metastatic cancer, 22 (32%) admitted to the ICU in the last two weeks of life reported having completed advance directives, though only 16 were available in the EMR.

Goals of care are elicited and used to formulate and document care-plan

Twenty-nine patients (42%) had goals of care documented in the EMR, though only 13 were documented prior to their terminal ICU admission.

TABLE 1. TOP 10 QUALITY MARKERS FOR THE END OF LIFE FOR ADULTS (UK) AND PROXY MEASURES USED IN STUDY^a

UK quality indicators	Proxy measures used in study EMR review to assess quality of EOLC
Institute effective mechanisms to identify those who are approaching the end of life	Assessment and documentation of prognostication in EMR
Ensure that people approaching the end of life are offered a care plan	Goals of care are elicited and used to formulate and document care plan
Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals	Documentation of advance directives in the EMR
Have mechanisms in place to ensure that care for individuals is coordinated across organizational boundaries 24/7	Documentation of POLSTs which are portable and valid across organizational boundaries
Ensure that the needs of caregivers are appropriately assessed and recorded	Assessment and documentation of caregiver stress in the EMR
Adopt a standardized approach (the Liverpool Care Pathway or equivalent) to care for people in the last days of life	Initiation of automated Comfort Care Order sets in EMR
Have an action plan for delivery of high-quality EOL care that encompasses all patients' diagnoses and is reviewed for impact and progress	These are the U.K. quality indicators for the health care system and thus not used in this study which focuses on quality indicators of EOL care for the individual patient
Have essential services available and accessible 24/7 to all those approaching the end of life who need them	
Be aware of EOL training opportunities and enable workers to access appropriate programs relevant to their needs	
Monitor the quality and results of EOL care and submit relevant information for local and national audits	

^aDepartment of Health: *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life*. London: Department of Health, 2008.

FIG. 1. Percentage of patients with metastatic cancer in the ICU near end of life whose care met specific quality markers. Patients were separated by whether or not they had palliative care consult.

Documentation of POLST forms which are portable and valid across organizational boundaries

The POLST form¹¹ is a portable legal order that specifies patient preferences for advanced therapies. This was used as the proxy to assess whether care was coordinated across organizational boundaries. Only 5 (7%) of the 69 patients had a completed POLST documented in the EMR.

Assessment and documentation of caregiver stress in the EMR

None of the patients had any documentation that caregiver needs and level of caregiver stress was assessed prior to the terminal hospitalization.

Initiation of automated comfort care order sets in EMR

The activation of inpatient medicine comfort care or ICU EOLC order sets was used as proxy for standardized approach to EOL care. These were implemented in 40 of the 69 patients (58%).

Palliative care consultation

Of the metastatic cancer patients admitted to the ICU in the last two weeks of life 28 (41%) had a palliative care consultation (PCC) 5.75 days (range 0–27 days) prior to death. Of these, only 5 patients (7%) had the PCC initiated prior to the ICU transfer. In comparing the subgroup that received the PCC to those who did not, the consult per se did not seem to influence the specific quality indicators utilized in this study. Three of the 28 patients who received PCC had a POLST form completed after initiation of consult. Of the 41 patients who did not receive a PCC, two had POLST completed. As the

number who received PCC was only 28 patients, the sample size was too small to make any conclusions about the effect of the PCC.

Site of death

Ninety-seven percent of patients who died of metastatic cancer did not leave the hospital. Fifty patients (72%) died in the ICU, 17 patients (25%) died in the hospital outside the ICU, and 2 patients (3%) were discharged to home. EMR records did not document these patients' preferred place of death.

Discussion

Most Americans want to die at home¹³ with peace and dignity¹⁴ and surrounded by their family. There is ample evidence^{15,16} that patients experience ineffective and burdensome medical care at the end of life. This was certainly true in the cohort of patients with metastatic cancer in our study who were admitted to the ICU in the last two weeks of life and died expected deaths with unmet quality markers of good EOL care. In these patients, the EMR did not show that prognostication was shared with patients or that the care plan was structured using a shared decision making model. Most did not have an advance directive/POLST or documented goals of care in the EMR. In the absence of prophylactic goals of care discussion and documentation, for seriously ill patients, the system default is to escalate technological interventions until it is compellingly clear to all stakeholders that the patient is dying. Sadly, this clarity often comes in the last few hours or days of life, at which time the discharge to home is not feasible for very practical reasons like clinician and family reluctance to erode the dying patient's dignity, as he or she may die during transit. Also, it takes time to initiate home hospice care, and if the patient dies at home before being admitted to home hospice, symptom management, as well as

practical issues like who will do the death pronouncement at home and sign the death certificate become important.

The care focus needs to shift from documenting just what is the matter with the patient to documenting what matters most to the patient in order for us to be able to avoid perpetrating ineffective and burdensome treatments on patients at the end of life. The swift current of mainstream medicine, with its default set at maximal interventions for all patients irrespective of the wisdom of doing so, has resulted in the ICU becoming the inevitable peri-death destination for even those dying expected deaths of known terminal illnesses like metastatic cancer. This erodes the dignity^{14–16} and quality of dying of patients, and causes tremendous emotional and financial burden to the family, in addition to causing significant moral distress to ICU staff who often find themselves in the invidious position of participating in ineffective interventions for these dying patients.

Data clearly show that early PCC aids complex decision making, matching the care provided with the patient's goals and values, and aids in mitigating the symptom burden. However in our study we are unable to draw any conclusions about the effect of PCC on the EOL quality measures evaluated, because only a small number of patients received a PCC, and 82% of these consults were peri-death consults following admission to the ICU, thus not allowing sufficient time for implementation of the consult recommendations. It should be noted that the automated comfort care order sets were implemented in a large percentage of the cancer patients dying in the ICU and were helpful in improving the quality of EOLC. These are cyber order sets that the admitting intern can implement immediately at any time of the day or night without a time lag invariably associated with any subspecialty consultation.

Finally, and most importantly, in our study cohort 97% of patients with metastatic cancer admitted to the ICU never did leave the hospital. Patients must be advised that often there is a small window of time in the trajectory of terminal illness during which their symptoms will allow them to be safely discharged and effectively managed at home. Thus, if patients truly desire to die at home, meticulous planning is required by which (1) the prognosis is estimated¹⁷ and communicated to the patient and family, (2) advance care planning is completed and documented in the EMR, (3) a POLST form is completed including the do-not-hospitalize option, and (4) their symptoms are managed aggressively in an outpatient setting (by palliative care in early stages of the illness and in home hospice in the last six months of life). In the event that these patients do get hospitalized, they may be best managed in a specialized palliative care bed (either the palliative care unit or the scattered bed model) instead of a regular acute care unit which often short-tracks them to the ICU.

Our study is limited by several factors. This was a retrospective chart review of decedents from a single academic medical center. The number of metastatic cancer patients who were admitted to the ICU was only 69 patients of the 2498 ICU admissions studied. The U.K. quality indicators were applied to U.S. patients, recognizing the health systems are different. However, seriously ill patients should have the same measures of quality, which is a key reason for international acceptance of the U.K. standards. We derived proxy measures for the six U.K. indicators utilized in this study.

Conclusions

Quality indicators for EOLC were mostly unmet in cancer patients admitted to the ICU in the last two weeks of life. Preventive palliative care very early in the trajectory of serious illness is vital in promoting good EOLC by eliciting and documenting patients' goals and values. All patients need to be educated that if they truly desire to die at home, careful planning is required to implement this. It is important to complete hospital-wide provider education about the need for early advance care planning with all seriously ill patients (which has been implemented recently at Stanford) in an effort to improve quality of care at EOL for hospitalized terminally ill patients.

Author Disclosure Statement

The authors have no conflicts of interest to declare.

Acknowledgments

The authors would like to thank STRIDE (Stanford Translational Research Integrated Database Environment), and particularly Gomathi Krishnan, PhD. STRIDE is supported by the National Center for Research Resources and the National Center for Advancing Translational Sciences, National Institutes of Health, UL1 RR025744. Dr. Periyakoil's work is supported in part by National Institutes of Health grants RCA115562A and 1R25 MD006857–01 and the Department of Veterans Affairs.

References

1. End of Life Curriculum Project, a joint project of the US Veterans Administration and SUMMIT, Stanford University Medical School.
2. Beccaro M, et al.: Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). *J Epidemiol Community Health* 2006; 60(5):412–416.
3. Townsend J, et al.: Terminal cancer care and patients' preference for place of death: A prospective study. *BMJ* 1990; 301(6749):415–417.
4. Higginson LJ, et al.: Place of care in advanced cancer: A qualitative systematic literature review of patient preferences. *J Palliat Med* 2000;3(3):287–300.
5. Institute of Medicine: *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press, 1997, pp. 33–49.
6. Center to Advance Palliative Care (CAPC). *America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals* 2008. www.capc.org/reportcard/. (last accessed August 28, 2013).
7. UK Department of Health: *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life*. London: Department of Health, 2008. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277. (Last accessed January 26, 2012.)
8. Gray B: *Issues in International Health Policy, England's Approach to Improving End-of-Life Care: A Strategy for Honoring Patients' Choices*. 2011. www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2011/Jul/1527_Gray_Englands_approach_endoflife_care_intl_brief_v2.pdf. (Last accessed January 26, 2012.)
9. Marie Curie Cancer Program and the Department of Health End-of-Life Care Programme: *National Care of the Dying*

- Audit - Hospitals (NCDABH)*. Round 3. Executive Summary. 2011/2012. www.rcplondon.ac.uk/sites/default/files/national_care_of_the_dying_audit_-_hospitals_exec_summary.pdf. (Last accessed January 28, 2012.)
10. Center for Disease Control: *Classification of Diseases, Functioning, and Disability*. 2011. www.cdc.gov/nchs/icd/icd10.htm. (Last accessed May 6, 2012.)
 11. Oregon Health and Sciences University: *Physician Orders for Life-Sustaining Treatment Paradigm*. www.ohsu.edu/polst/. 2008. (Last accessed March 19, 2012.)
 12. Oken MM, et al.: Toxicity and response criteria of the Eastern Cooperative Oncology Group. *Am J Clin Oncol* 1982; 5:649.
 13. Fontana A, Keene JR: *Death and Dying in America*. Cambridge, UK: Polity Press, 2009, p. 30.
 14. Periyakoil VS, Stevens M, Kraemer H: Multicultural long-term care nurses' perceptions of factors influencing patient dignity at the end of life. *J Am Geriatr Soc* 2013;61(3): 440-446.
 15. Periyakoil VS, Noda AM, Kraemer HC: Assessment of factors influencing preservation of dignity at life's end: Creation and the cross-cultural validation of the preservation of dignity card-sort tool. *J Palliat Med* 2010;13(5):495-500.
 16. Periyakoil VS, Kraemer HC, Noda A: Creation and the empirical validation of the dignity card-sort tool to assess factors influencing erosion of dignity at life's end. *J Palliat Med* 2009;12(12):1125-1130.
 17. Moss AH, Lunney JR, Culp S, Auber M, Kurian S, Rogers J, Dower J, Abraham J: Prognostic significance of the "surprise" question in cancer patients. *J Palliat Med* 2010;13(7):837-840.

Address correspondence to:
Jennifer A. Blechman, MD
c/o Partners in Care
2075 Newyatt Court
Bend, OR 97701

E-mail: jblechman@bendcable.com