

Measuring end-of-life care in oncology practices: learning from the care of the dying

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Background There is increased interest among oncology and palliative professionals in providing appropriately timed hospice services for cancer patients. End of life (EoL) metrics have been included in oncology quality programs, but accurate EoL data and benchmarks are hard to obtain.

Objective To improve EoL care by measuring patterns of care among recently deceased patients.

Methods Care utilization among deceased patients was analyzed by using software integrated with patient electronic health records. The data was verified by chart review.

Results Of 179 cancer deaths, tumor registry data differed from chart review in 7% of cases with regard to dates and/or location of death. Institutional EoL metrics were significantly affected by a large number of patients (37%) with advanced illnesses who had clinical diagnoses of cancer made at the end of life, but who had not been managed by oncologists. This population of patients who had not been managed by oncologists was older, less likely to use hospice, and more likely to use the intensive care unit than were oncologist-managed cancer patients. Among the patients of individual oncologists, the median stay in hospice ranged from 6-28 days. Data collection and chart review took an average of 27 minutes per case with combined efforts by a data analyst and oncology practitioner.

Limitations Single institution with comprehensive electronic medical record; some patients were treated outside of the system.

Conclusion Acquiring accurate data on EoL metrics is time consuming. Compared with chart review, other data sources have inaccuracies and include some patients who have not been managed by oncologists. Accurate attribution to individual physicians requires chart review by an experienced clinician.

The care of cancer patients at the end of life has attracted increased scrutiny from oncology and palliative care professional societies, health economists, and an array of critics both internal and external to oncology. The detractors point to the provision of futile cancer care delivered at huge cost in too many patients.¹ The problem is not just of costs; study findings indicate that use of palliative care and hospice care prolong life and improve patient quality of life and caregiver satisfaction,² but that these services are often underused and initiated too late in the dying process to benefit patients and families.³ As a result, quality organizations such as the National Quality Forum⁴ and professional societies such as the American Society of Clinical Oncology (ASCO) and its Quality Oncology Practice Initiative (QOPI) have invested in educational tools and the development of measurements of end of life (EoL) care.⁵ Among these metrics are: location of death, hospitalization rates, use of intensive care support, chemotherapy use, and enrollment in hospice

care near the time of death. Professional societies have written guidelines for EoL care that emphasize timely introduction of palliative care and avoidance of overly aggressive care. The QOPI, a quality framework for oncology practices, uses some measures of EoL care as a quality metric and is testing others.^{6,7}

But medical oncology practices do not generally possess the tools to easily track their own data nor do they have access to relevant local and national benchmarks. Nationally reported benchmarking data such as the Dartmouth Atlas⁸ rely on claims data of a representative sample of Medicare patients, which are only a subgroup of patients seen in most practices. Furthermore, these data are hospital-based through a methodology that assigns patients to a hospital from which the predominance of medical claims arise. Analyzing this data may be helpful for hospital administrators and health services researchers but it is not helpful to practices in the common situation in which individual practices attend at more than one hospital or are associated

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with hospitals in which more than one practice contributes to oncology care.

We performed a quality performance review of recent oncology related deaths at a single medical center to obtain EoL metrics and to determine the feasibility of gathering accurate data for attribution to particular practices or individual managing physicians.

Patients and methods

The Clinical Research Committee, the scientific oversight board for clinical studies at Anne Arundel Medical Center approved this study with a waiver of Institutional Review Board and of informed consent based on current guidelines from the Office of Human Research Protections.⁹

Setting

Anne Arundel Medical Center is an acute care hospital in Annapolis, Maryland, licensed for 385 beds. The oncology program sees more than 1,800 new analytic cases annually and serves as a regional referral center for communities in eastern, southern, and central Maryland. Three separate medical oncology and hematology practices attend at the hospital. The staff of 2 of the practices are employed by the medical center, have offices on the hospital campus, and exclusively use the hospital-administered outpatient infusion center on campus. All three practices admit patients when necessary to the inpatient oncology floor. Inpatient palliative care consultation services are provided by employees of the local hospice provider.

Cancer death database

All cancer-related deaths occurring between April 1, 2013 through April 30, 2014 that were registered in the Anne Arundel Medical Center tumor registry were included for analysis. The cutoff date was 2 months before the time of analysis to allow for notice of deaths to reach the tumor registrar. The tumor registry receives notification about dates of deaths from practitioners, local obituaries, State of Maryland Death Clearance (a review of state death certificates), and from Elekta Metriq, a vendor that reviews social security databases. Patterns of care and use of services was obtained by using Crimson (The Advisory Board Company, Washington, DC), a software analytic tool that is integrated with coded clinical data. To verify coded data and attribute to individual physicians, individual electronic medical records (Epic, Aurora, WI) were reviewed. To analyze the data further and attribute outcomes to individual outpatient physicians, we performed additional analysis of patient records, including chemotherapy flow sheets, inpatient and outpatient progress notes, admission and discharge notes, and telephone encounters. Some data were retrieved from the main local hospice provider.

We used the Student's t-test for independent samples

to perform statistical comparisons between two populations of patients: those with cancer managed by oncologists (oncologist-managed), and those with an end-of-life diagnosis of cancer not managed by oncologists (nonmanaged).

Results

In all, 181 consecutive deaths in cancer patients were identified by the tumor registry during the study period. Two patients did not have cancer and were excluded from further analysis. No other patient was found to have died of a cause other than cancer in this sample. Reviews of higher-level databases (eg, tumor registry and hospice databases), coded data, and charts to determine hospitalization rates and length of stay took on average 15 minutes when performed by a nonmedically trained analytics researcher. More detailed chart reviews to follow the path of care and determine the attributable physicians and chemotherapy use took an experienced oncologist another 12 minutes on average. We found data discrepancies between the electronic medical record and higher-level databases in 7% of cases.

More significantly, the review of individual records led to an unanticipated finding: 68 of 179 "cancer" patients (38%) had not been managed by any of the 3 oncology groups attending at the medical center. Six of the 68 nonmanaged patients were being treated at other medical centers at the time of their deaths, including 2 at a quaternary referral center, and 4 at smaller community hospitals. The remaining 62 nonmanaged patients were not known to have cancer until symptoms or a declining performance status lead to a hospital admission, generally very close to the time of their death. According to Maryland State rules, the tumor registry must record all patients who have a clinical diagnosis of cancer at the time of death whether or not a biopsy has been performed. Under this understanding, the use in the medical record, of indistinct but common clinical terms such as "suspicious for [cancer]," "consistent with [cancer]," and "likely malignant" in diagnostic reports or clinical notes qualify patients as having a cancer diagnosis, whether or not a tissue biopsy or diagnostic lab test has been performed or an oncologist has been consulted. Of the 62 patients whose cancer diagnosis was made in that way, 56 were assessed as likely to have cancer by radiographic findings, 4 by physical exam findings, and 2 by blood test results. Biopsy was not performed in any of these patients, and oncologists were only consulted in 5 of the cases. In general, other medical problems such as dementia, debility, end-stage renal failure, and/or heart failure led the patient or health care proxy to decline biopsy, further evaluation, or treatment.

The EoL metrics for the 111 patients managed by our hospital oncologists and the 68 nonmanaged patients are shown in the Table. The nonmanaged population differed from the managed-oncology population in that it had a

higher median age, a lower use of hospice, and a higher rate of hospitalization and use of the intensive care unit within 30 days of death. There was no difference between the groups with regard to hospice length of stay or how many had 0-3 days in hospice.

The breakdown of patient length of stay in hospice by attributable oncologist is shown in the Figure. The 9 physicians for whom there was adequate data sorted into one of two groups: median length of stay of 15 or more days (4 physicians, 44 patients), or median length of stay of less than 9 days (5 physicians, 63 patients). The data for 2 doctors (4 patients) was not included in the figure because of the low numbers.

Discussion

Increased attention to EoL metrics for oncology practices is appropriate because of the strong data that supports appropriately timed intervention with hospice care and cessation of chemotherapy. It has been pointed out that location of death is not, by itself, a useful indicator of poor quality care if this process is in accordance with the patient's expressed wishes.¹⁰ Indeed, the modern oncologist practices in a setting in which "shared medical decision making" is highly valued.^{11,12} Every oncologist can share anecdotes about aggressive end-of-life care driven by patients and/or their families. Patient expectations about the outcome of cancer treatments for advanced stage disease tend to be overly optimistic,¹³ but it has also been observed that oncologists are often followers in the end-of-life process, deferring conversations until serious medical complications intervene and then allowing others in the care team to take the initiative.¹⁴ For some physicians, acceding to a patient's wishes is a responsibility fulfilled. Others would argue that failing to protect their patients and their families from the anguish that comes from intensive but futile care is indeed a marker of poor quality.¹¹ Either way, it is important for practices to gather and analyze data on EoL care in an effort to find ways to improve. These circumstances would make regional and national EoL benchmarks useful, but they do not exist at a practice level. There are some hospital-based benchmarks, but as demonstrated in this paper, they do not reflect the actual care given by individual practices or physicians.

Our study shows that collecting reliable data is time con-

TABLE End of life metrics for deceased patients diagnosed with cancer

	Managed (n = 111)	Nonmanaged (n = 68)	P value
Median age, y (range)	71 (37-88)	77 (73-91)	
Gender ratio, %			.01
Female	39	49	
Male	61	51	
Location of death, n (% of all deaths)			.01
Unknown	12 (10.8)	9 (13.2)	
Total in hospice	80 (71)	39 (57)	
Home	64	30	
Inpatient	16	9	
Rehab or nursing facility	1 (1)	15	
Home without hospice	18 (16)	5	
Median LoS in hospice, d	8	7	NS
% with hospice stay of 0-3 d	16	17	NS
ChemoRx within 14 d of death, n (%) [median d]	7 (6.3) [7]	Not applicable	Not applicable
Hospital admissions within 30 d of death, n (%) [median LoS in d]	65 (48.5) [5]	41 (60.2) [6]	.01
Intensive care within 30 d of death, n (%) [median LoS in d]	5 (4.5) [4]	8 (11.8) [8]	.001

LoS, Length of stay; ChemoRx, chemotherapy; NS, not significant ($P > .05$)

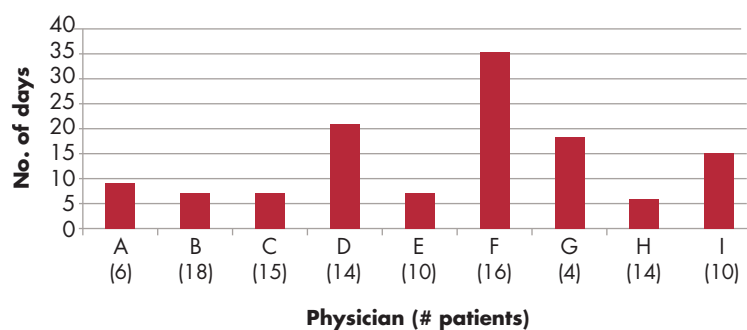


FIGURE Median hospice LoS by physician
LoS, length of stay

suming but enlightening when it is obtained. We found that higher view analyses of databases was discordant with detailed medical record review in 7% of cases. But the biggest concern with the reporting of high view data is the surprising finding that 38% of "attributed" cancer patients were not patients actively managed by oncologists. Rather they were most often patients who were hospitalized toward the end of their life with clinical findings consistent

with cancer. Despite the lack of a biopsy or a consult with an oncologist, the data for these “cancer” patients data is intermingled with oncologist-managed oncology patients, which allows for misinterpretation of the EoL metrics as the 2 populations have important differences. This result, if reproduced elsewhere, has profound implications for the reporting of EoL metrics. Depending on the intended use of the data, one cannot rely on high-level databases to accurately determine the performance of a practice or individual doctors with regard to EoL care. Indeed, the impact of such a large minority of nonmanaged “cancer” patients would obscure any improvements made by oncology programs or practices to improve EoL care.

Unfortunately, this means that accurate information, especially where attribution to physicians is desired, will require detailed chart review. Failure to do this will result in loss of confidence by the physicians in the data with the resulting inability to generate practice change. Granular chart review is time consuming even for experienced clinicians, something that should be recognized before these metrics become mandated. However, oncology practices will find the effort worthwhile in attempting to demonstrate value to insurers, employers, or primary care colleagues who participate in new arrangements such as accountable care organizations, collaborative care networks, or medical home arrangements, each of which has shared savings formulae.

Our study is limited by the fact that it took place at a single setting at a hospital-based program. However, this is an increasingly common arrangement for cancer care in the United States. We also benefited by having access to electronic databases from the local hospice provider. We had access to the entire medical record for nearly all of the patients in the study. Hospitals or practices without this level of shared electronic health record will have to use different and more cumbersome methods to extract the same information. Finally, in this study, only 6 patients were managed at other hospitals during their end of life. Other practices and programs may have much higher percentage of patients who receive part of their care outside their system, making it both harder to get information and inappropriate for those patients’ results to be attributed.

It must be acknowledged that the validity of the EoL metrics used in this study has been disputed. Some have argued that chemotherapy given with a palliative intent should not be regarded as inappropriate no matter when it is given.¹⁵ A similarly performed study to ours by Adam and colleagues made a distinction between EoL chemotherapy that was continued forward and regimens that were newly initiated within 14 days of death, suggesting that the former was acceptable and the latter ill-advised.¹⁶

The presence of an existing set of EoL benchmarks does not mean there is no room for new benchmarks. Indeed, measuring the satisfaction in the care and communication

among dying patients and their families could and should be routinely included. One can envision a new type of morbidity and mortality conference in which all team members review the EoL experience of deceased patients with the goal of improving processes. Improving care at the end of life remains an important goal for our profession.

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