

End-of-Life Care Discussions in Patients With Advanced Cancer

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The Oncology Grand Rounds series is designed to place original reports published in the Journal into clinical context. A case presentation is followed by a description of diagnostic and management challenges, a review of the relevant literature, and a summary of the authors' suggested management approaches. The goal of this series is to help readers better understand how to apply the results of key studies, including those published in Journal of Clinical Oncology, to patients seen in their own clinical practice.

A 70-year-old man with a history of a Gleason 9 (4 + 5) adenocarcinoma 10 years before that was treated with a radical prostatectomy presented to his primary care physician with a complaint of rectal pain that had persisted for several weeks. A large palpable mass was found on a digital rectal exam and was noted on sigmoidoscopy to cause extrinsic compression of the rectum. A biopsy of the perirectal mass was consistent with metastatic carcinoma that was consistent with a recurrent metastasis of his previous prostate adenocarcinoma, now with small-cell transformation. A computed tomography scan showed the perirectal mass arising from the prior prostatectomy bed, as well as a large hepatic mass and bilateral lung nodules that were consistent with metastatic disease (Fig 1). He had lost 20 lbs over 3 to 4 weeks and complained of progressive fatigue, poor appetite, severe tenesmus, and rectal pain.

He presented to the medical oncology department for an initial consultation. Given his significant rectal pain and declining functional status, he was referred for palliative pelvic radiation to be given with concurrent single-agent chemotherapy. The patient had been living independently on the West Coast but had relocated to the East Coast to be closer to his adult children. He stressed that his wishes were to remain as independent and functional as possible. He named his eldest son as his health care proxy but did not have an advance directive or living will. After the visit, the patient's daughter approached the oncologist with concerns about discussing "CPR" (cardiopulmonary resuscitation) and "life support," and indicated that this discussion would be overwhelming for her father.

CHALLENGES IN DIAGNOSIS AND MANAGEMENT

Caring for patients near the end of life (EOL) is an important task for oncologists. A significant proportion of patients with advanced cancer receive intensive medical therapy in the final days of life. One third of patients with advanced disease receive chemotherapy within 30 days of death, and approximately 16% receive treatment within the last 2 weeks of life.¹ Approximately 10% of patients have an acute hospitalization or intensive care unit (ICU) admission in the last month of life.¹ Overall, there has been a recent general trend toward increasing intensity of medical therapies in patients with cancer.¹

Cardiopulmonary resuscitation (CPR) is perhaps the most intensive form of care delivered in the hospital or ICU setting. Unfortunately, the chance of survival after cardiopulmonary arrest in patients with advanced cancer is small, with only approximately 5% of patients alive at discharge from the hospital.²⁻⁷ Beyond the

poor medical outcomes for patients, there can be collateral damage from intensive medical interventions at the EOL. Caregivers of patients who died in the ICU were more likely to suffer from post-traumatic stress disorder than caregivers of patients who died at home under hospice care.⁸ This observation attests to the importance of improved communication between clinicians and patients about intensive EOL care and resuscitation.

EOL care discussions can improve the dying experience for both patients and their families.^{9,10} Data demonstrate that patients facing serious illnesses prefer to actively participate in EOL care planning.¹¹⁻¹⁴ Patients with advanced cancer desire frank discussions with their clinicians about their prognosis and preferences for care at the EOL, preferably early in the course of disease.¹⁵⁻¹⁷ However, even in patients with a prognosis of less than 1 year, only a minority report having discussions about care at the EOL with their oncology clinicians.^{18,19} In the landmark SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of

SUMMARY OF THE RELEVANT LITERATURE

Currently, discussions about EOL care occur late in the course of disease, often in the inpatient setting. However, the optimal timing of EOL care discussions is early in the course of disease, and preferably in an ambulatory care setting.^{1,23-26} Recent data show that EOL care discussions that occur before the last 30 days of life are associated with lower rates of receipt of chemotherapy and acute hospital/ICU care.²⁷ Additionally, the outpatient setting provides an ideal environment for a multidisciplinary approach to EOL communication, giving patients access to psychosocial and palliative care to guide decision making well in advance of an acute, life-threatening illness during which patients may lack the capacity to make medical decisions.^{23,24,26} Such ideal discussions take place all too infrequently. Over half (55%) of patients with advanced lung or colorectal cancer who had documented EOL care discussions with their providers did so in the context of an emergency room visit or inpatient hospitalization.²⁸ Even when EOL care discussions do take place in the ambulatory setting, rates of documentation of patient preferences is quite low, ranging from 6% to 20%.^{29,30}

Patients who actively participate in medical decision making report greater satisfaction with quality of care and better alignment between the care received and their preferences.³¹⁻³³ However, only a minority of patients report a truly shared approach to decisions.³⁴ The Affordable Care Act promotes the shared decision-making process through several channels,³⁵ including patient decision aids, which are evidence-based tools used to provide patients with information about risks and benefits of treatments.³⁶

There is a growing body of literature examining the use of patient-targeted decision aids to facilitate improvements in knowledge and discussions about EOL care (Table 1).^{37-39,42} Patients' use of a question prompt list led to more discussions regarding prognosis and EOL care, left fewer unmet information needs, and enabled patients to have more time with their providers.³⁷ Patients who watched a video decision aid depicting various levels of care were more likely to opt for comfort care and forego resuscitation than those receiving verbal information alone.³⁹ Decision aids have been shown to be effective in increasing knowledge and increasing the likelihood that patients will receive care that reflects their values,⁴³ and may be a valuable resource to oncology clinicians in helping patients plan for the EOL.

In the accompanying article by Stein et al,⁴⁰ the investigators conducted a randomized trial of an intervention that consisted of a patient pamphlet and a discussion with a psychologist that was based on a shared decision-making model compared with usual care. Their outcome measures included the proportion of patients with DNR orders, the timing of DNR orders, and place of death. They also evaluated knowledge of CPR, mood, and caregiver burden. The pamphlet included information on key domains of advanced cancer care: communication with the health care team, anticancer treatments, symptom management, psychosocial care, and advance care planning, and was reviewed by both patients and members of multidisciplinary oncology teams.⁴⁰ The discussion with the psychologist was based on a shared decision-making model and was structured around four topics: communication with providers, symptom burden, palliative and psychosocial care, and EOL care planning.^{40,44}

Equal rates of DNR orders were observed in the intervention and control groups (68% v 76%, respectively). However, among patients

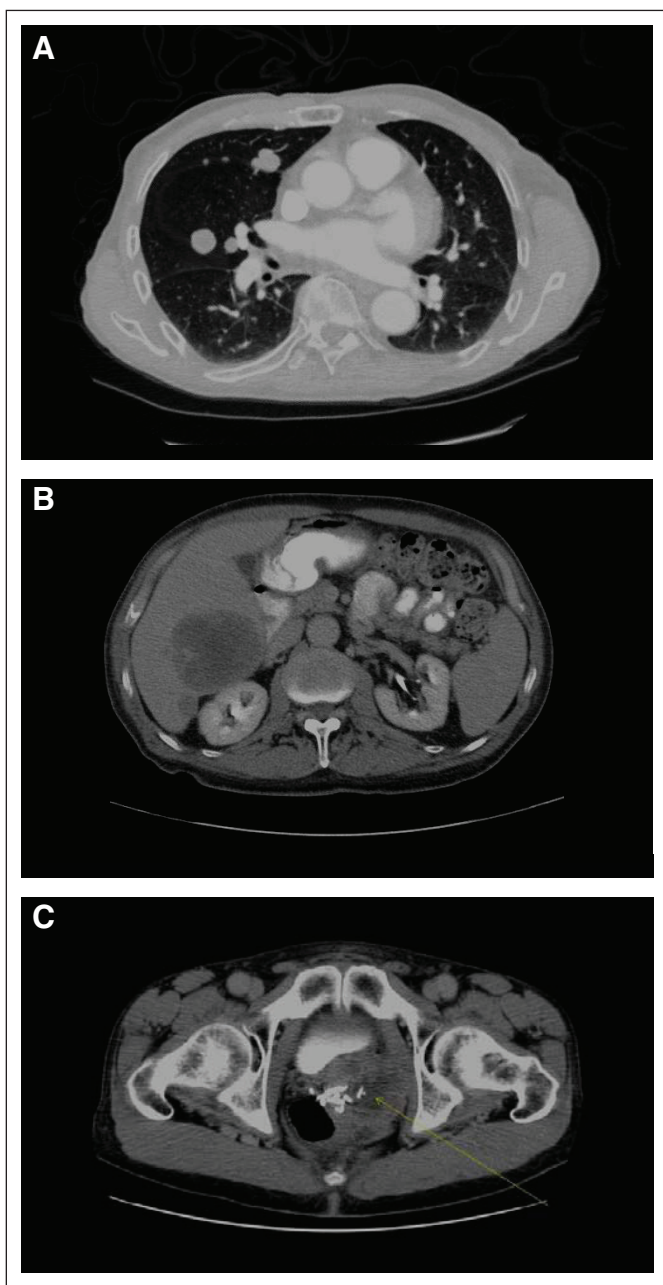


Fig 1. (A) Computed tomography (CT) scan image showing bilateral lung metastases. (B) CT scan image showing large liver metastasis. (C) CT scan image showing soft tissue mass (arrow) arising from the prostatectomy bed.

Treatments) trial, over half of physicians (53%) were unaware of their hospitalized patients' wishes to avoid resuscitation.²⁰ Nearly half of these patients lacked documentation in the form of a do-not-resuscitate (DNR) order in their medical record.²⁰ Additionally, 46% of DNR orders were entered only within 48 hours of death. Notably, recent data suggest that patients who are able to have EOL care discussions with their oncologists receive less intensive medical therapy at the EOL and earlier enrollment in hospice.²¹ Patients with cancer are also more likely to receive care that is consistent with their preferences if they have had the opportunity to discuss EOL care with their oncologists.²²

Table 1. Clinical Trials of Interventions to Improve EOL Care Discussions and Documentation in Patients With Cancer

Reference	Target Group	Design/Intervention	No. of Participants	Results
Patient-targeted interventions				
Clayton et al, 2007 ³⁷	Patients with advanced cancer, caregivers	RCT of QPL and physician endorsement of use v standard care	174 (QPL, 92; control, 82)	Intervention (QPL) arm v control arm: Asked more questions (ratio, 2.3; 95% CI, 1.7 to 3.2; <i>P</i> < .001) Discussed more prognostic issues (ratio, 1.43; 95% CI, 1.1 to 1.8; <i>P</i> = .003) Discussed more EOL issues (30% v 10%; <i>P</i> = .001)
El-Jawahri et al, 2010 ³⁸	Patients with malignant glioma	RCT of video decision aid on EOL care v verbal description of EOL care	50 (video, 23; verbal, 27)	Intervention (video) arm: 0% preferred life-prolonging care; 91.3% preferred comfort care Control (verbal) arm: 25.9% preferred life-prolonging care; 22.2% preferred comfort care (<i>P</i> < .001)
Volandes et al, 2013 ³⁹	Patients with advanced cancer	RCT of a video decision aid v verbal narrative for CPR decision-making and preferences	150 (video arm, 70; control arm, 80)	Intervention (video) arm: 20% wanted CPR; 79% wanted no CPR Control (verbal) arm: 48% wanted CPR; 51% wanted no CPR (<i>P</i> < .001)
Stein et al, 2013 ⁴⁰	Patients with advanced cancer, caregivers	RCT of written and discussion intervention v standard care on rate and timing of DNR orders, and place of death	120 (intervention, 55; control, 65)	Intervention arm v control arm: Rates of DNR orders equivalent Median time to DNR order: 27 v 12.5 days (<i>P</i> = .03) Hospital death: 19% v 50% (<i>P</i> = .01)
Physician-targeted interventions				
Temel et al, 2013 ⁴¹	Oncology providers of patients with advanced lung cancer	Nonrandomized, historical control study of clinician-directed electronic prompts on rate of code status discussion documentation	200 (intervention, 100; historical controls, 100)	Intervention arm v historical controls at 1 year: Code status documentation in EMR: 33.7% v 14.5% (<i>P</i> = .003) Mean time to code status documentation: 8.6 v 10.5 months (<i>P</i> = .004)

Abbreviations: CPR, cardiopulmonary resuscitation; DNR, do not resuscitate; EOL, end of life; EMR, electronic medical record; QPL, question prompt list; RCT, randomized controlled trial.

who completed the study, DNR orders were written significantly earlier for patients in the intervention group (median 27 v 12.5 days; *P* = .03). Patients who received the intervention were also less likely to die in the hospital (19% v 50%; *P* = .004). Although the two groups did not differ with respect to knowledge of CPR, the intervention group had more accurate estimates of success of CPR. Importantly, there was no increase in patient-reported psychological distress in the intervention group, and caregivers of patients in the intervention group reported lower burden (*P* = .05). This is the first patient-centered intervention in a randomized trial setting to affect the timing of DNR orders and place of death. Additionally, the intervention resulted in a more accurate understanding of the success of CPR in patients with advanced cancer. Although the data from this study and other studies of patient-directed interventions using decision aids are encouraging,^{38,39,42} there is a clear need for the development of targeted interventions that are aimed at both patients and providers to improve documentation of patients' EOL care preferences.

SUGGESTED APPROACHES TO MANAGEMENT

Despite the emerging body of evidence that suggests that early EOL care planning as part of routine cancer care is beneficial, current practice for patients with advanced cancer is inadequate. Many patients and families face difficult decisions at the EOL, often without having had the opportunity to express their concerns and

preferences to their oncology clinicians. Several studies, including the accompanying article,⁴⁰ demonstrate the efficacy of various interventions in improving patient knowledge^{37-39,42} and the rate and timing of EOL discussions.⁴¹ These data underscore the need for large-scale, randomized trials of both patient- and provider-directed interventions to demonstrate efficacy of such tools across multiple cancer populations and health settings. The literature also confirms the need for implementation of educational programs for oncology trainees and clinicians to enhance physician performance in discussing patients' EOL care preferences. Unfortunately, patient- and provider-directed interventions and education are not generally available or in widespread use at the current time. Without the necessary tools and training, oncologists often defer conversations about EOL care until patients are very ill or have been admitted to the hospital.⁴⁵

In an effort to establish a standard of care for advance care planning, the National Comprehensive Cancer Network guidelines for Palliative Care recommend that clinicians initiate comprehensive discussions about EOL care preferences and goals for all advanced patients with cancer with prognoses limited to less than 1 year.⁴⁶ Initiating these discussions earlier in the course of illness allows patients the opportunity to participate in multiple conversations with their health care providers and their family members. This strategy is in stark contrast to the more common practice in which patients are asked to make rapid decisions about CPR while in the hospital or emergency room without adequate time to weigh their care options.

Ensuring patients have an accurate understanding of their prognosis and goals of care, before starting cancer-directed therapy, is an important step for future discussions about EOL care preferences. Patients who have a more accurate understanding of their prognosis are more likely to defer medical interventions and resuscitation at the EOL.²¹ Thus, by informing patients that their cancer is incurable and that the goal of therapy is to prolong life rather than cure the disease, oncologists can lay the groundwork for patients to make decisions about their care preferences at the EOL.⁴⁷ Oncologists should initiate conversations about prognosis and goals of therapy intermittently throughout the course of illness to ensure patients and their families understand that treatment is palliative in nature. One suggested approach is for oncologists to address prognosis and goals of therapy when discussing the possibility of another line or chemotherapy versus supportive care alone after cancer progression.

Changes in patients' clinical status as a result of either progressive symptoms or cancer growth on radiographic studies can also serve as a trigger for oncologists to initiate discussions with patients about their EOL care preferences.⁴¹ One suggested approach for this conversation is the "hope for the best and prepare for the worst" technique.⁴⁸ For example, the oncologist can begin the discussion with: "Although we hope that this new chemotherapy will stop your cancer from growing further, there is a chance it will not, and we should start discussing your preferences for care if that occurs." It can be helpful to educate patients who have advanced cancer that with their current health status, it is unlikely that heroic measures, such as CPR, will meaningfully impact their survival.

When cancer-directed therapy is no longer an option because of a patient's poor clinical status or lack of available potentially efficacious treatments, it becomes imperative to discuss the patient's EOL care preferences. One suggested approach for initiating conversations in this situation is to explain the option and benefits of hospice now that the patient will no longer be receiving cancer-directed therapy. Explaining that the goal of hospice care is to ensure that patients and their families receive the care and support that they need as the patient becomes more ill can easily transition into a discussion of their specific EOL wishes and preferences.

The National Comprehensive Cancer Network guidelines for Palliative Care also recommend referral to specialist palliative care in situations in which patients have difficulty engaging in EOL care discussions or if there is disagreement among the patient, family members, and/or the health care team regarding risks and benefits of interventions. Palliative care is a useful resource for assisting with discussions about patients' EOL care preferences.⁴⁹ Unfortunately, many oncologists do not have access to palliative care specialists in either the hospital or ambulatory care setting.

In the case of our patient with recurrent, widely metastatic prostate carcinoma with small-cell transformation, given his significant symptom burden and the family's concerns about discussing EOL care, our approach to advance care planning was multidisciplinary and took place over the course of several months. At the initial visit, we communicated to the patient and his family that his disease was incurable and that the goals of therapy would be palliative in nature. We also had a frank discussion about his limited prognosis, which we estimated was less than 1 year. Because of the concerns of his daughter and his significant symptom burden, we initially deferred a discussion about his EOL care preferences and focused on starting palliative treatment with chemotherapy and radiation. Within a month of our

initial consultation, we referred him to the outpatient palliative care service for comanagement of his significant symptoms of rectal pain, tenesmus, and insomnia. He was also referred to psycho-oncology for assistance with his mood and was observed closely by an oncology social worker for additional supportive counseling.

Given that we were unable to completely ascertain the patient's wishes for life-sustaining treatment and other specific aspects of EOL care at the initial consultation, we continued to readdress these issues at subsequent visits. Within a month of our initial visit, we initiated a conversation about the patient's goals and personal values. He stated that he valued autonomy and independence most and that he feared burdening family members. His main goal was to live independently once his symptoms and functional status improved. We held several discussions with the patient and his children about the rationale for completing an advance directive, particularly in the context of his clearly stated personal goals and values. We discussed life-sustaining and life-prolonging measures in detail, but the patient preferred to consider these options over the next few weeks before completing an advance directive.

We partnered with our palliative care and social work colleagues to provide support to the patient's children and to foster a shared understanding of his prognosis and goals. We stressed that, although discussions about EOL care can be difficult, they are integral to providing care that is compatible with the patient's wishes. Over the course of several visits, the patient's daughter became more comfortable with discussing these often emotionally fraught topics. On completion of therapy, the patient reported near resolution of his pelvic pain. Scans demonstrated stability of the rectal mass but enlarging pulmonary and hepatic metastases. Although he remained asymptomatic, we reaffirmed the incurable nature of his cancer and his limited prognosis. We also discussed treatment options, including second-line chemotherapy and palliative care with home hospice, emphasizing that all options were palliative in nature. The patient desired a break from any further therapy for several weeks and some time to consider options for care.

Six weeks later, repeat imaging showed progressive metastases, although the patient remained asymptomatic. Although he wanted to keep the option of future therapy open, he stated that his immediate goals were to spend time with his family and friends, and he deferred chemotherapy. During the following few weeks, he verbalized to his children and care team that he preferred to die at home and avoid resuscitation in the event of cardiopulmonary arrest. We documented these wishes in the electronic medical record, 5 months after our initial consultation. The patient continued to defer additional cancer-directed therapy and enjoyed 5 months of living independently with a good quality of life. He ultimately enrolled in home hospice when his functional status declined, and he died surrounded by his family 1 month later.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

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