

Longitudinal Perceptions of Prognosis and Goals of Therapy in Patients With Metastatic Non–Small-Cell Lung Cancer: Results of a Randomized Study of Early Palliative Care

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ABSTRACT

Purpose

Understanding of prognosis among terminally ill patients impacts medical decision making. The aims of this study were to explore perceptions of prognosis and goals of therapy in patients with metastatic non–small-cell lung cancer (NSCLC) and to examine the effect of early palliative care on these views over time.

Patients and Methods

Patients with newly diagnosed metastatic NSCLC were randomly assigned to receive either early palliative care integrated with standard oncology care or standard oncology care alone. Participants completed baseline and longitudinal assessments of their perceptions of prognosis and the goals of cancer therapy over a 6-month period.

Results

We enrolled 151 participants on the study. Despite having terminal cancer, one third of patients (46 of 145 patients) reported that their cancer was curable at baseline, and a majority (86 of 124 patients) endorsed getting rid of all of the cancer as a goal of therapy. Baseline perceptions of prognosis (ie, curability) and goals of therapy did not differ significantly between study arms. A greater percentage of patients assigned to early palliative care retained or developed an accurate assessment of their prognosis over time (82.5% v 59.6%; $P = .02$) compared with those receiving standard care. Patients receiving early palliative care who reported an accurate perception of their prognosis were less likely to receive intravenous chemotherapy near the end of life (9.4% v 50%; $P = .02$).

Conclusion

Many patients with newly diagnosed metastatic NSCLC hold inaccurate perceptions of their prognoses. Early palliative care significantly improves patient understanding of prognosis over time, which may impact decision making about care near the end of life.

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INTRODUCTION

Despite the advent of novel therapies, metastatic non–small-cell lung cancer (NSCLC) remains an incurable disease that causes significant morbidity and has a high symptom burden.¹⁻³ Although some patients experience improvement in their symptoms with anticancer therapy, the time to disease progression is often only a few months.⁴⁻⁶ A realistic understanding of prognosis and the goals of cancer therapy will help inform treatment decisions for patients with short life expectancy receiving intensive chemotherapies.⁷⁻⁹ Patients with advanced cancer who have poor illness understanding and overestimate their prognosis are more likely to choose aggressive medical care at the end of life.¹⁰⁻¹² An

accurate illness understanding may aid in preparing for the end of life by not only allowing patients to choose care that is congruent with their goals and wishes but also potentially mitigating the trend of increasingly aggressive and costly cancer care.¹³⁻¹⁶

Even when presented with accurate information about their diagnoses, patients with advanced cancer frequently retain inaccurate perceptions of their illness. Researchers conducting a study on the utility of a treatment decision aid for patients with metastatic NSCLC observed that all 20 participants believed their cancer was curable, despite reviewing educational materials that explicitly stated that their illness would not be treated with curative intent.¹⁷ Moreover, in an investigation of 181 patients with advanced cancer receiving palliative therapies, one

third of participants reported an aim of treatment to be cure, both at the time of study entry and 12 weeks later.¹⁸ To date, no studies have shown any benefit from interventions designed to clarify perceptions of prognosis among patients with advanced cancer. Considering these sobering findings, additional research is needed to develop practical and evidence-based interventions that improve illness understanding in patients with advanced cancer.

One approach to enhance accuracy in perceptions of prognoses and goals of treatment among patients with advanced cancer is to facilitate discussions about these topics throughout the course of the disease.¹⁹ Some patients may be ready to discuss these topics in depth at their initial consultations, whereas others, such as those with psychosocial distress, may need more time to consider the prognosis.²⁰ Interventions would ideally be tailored to the individual needs of patients.²¹ Early access to palliative care services soon after diagnosis has the potential to be such an intervention.²² In addition to providing supportive care focused on the physical, psychological, spiritual, and cultural aspects of illness, palliative care clinicians enable patients to make informed treatment decisions by educating them about the disease, prognosis, and potential benefits and burdens of medical therapies.²³

Individuals with advanced cancer typically receive palliative care consultations late in the course of illness, limiting the opportunity for clinicians to intervene and educate patients about the disease process while undergoing cancer treatment.²⁴⁻²⁶ Our group and others have demonstrated that early involvement of palliative care in the ambulatory care setting is feasible.²⁷⁻³⁰ However, researchers have not examined the effect of such interventions on illness understanding of

patients. We performed a randomized, controlled trial of early palliative care integrated with standard oncology care versus standard oncology care alone, observing significant improvements in quality of life, mood, and survival among patients with metastatic NSCLC who received early palliative care.³¹ The aims of the present analysis were as follows: to assess the accuracy of patient perceptions of prognosis and goals of cancer therapy; to examine the effect of early palliative care services on patient illness perceptions over a 6-month period; and to explore whether changes in illness perceptions were associated with the care patients received at the end of life.

PATIENTS AND METHODS

Study Design

Ambulatory patients with newly diagnosed metastatic NSCLC participated in a randomized, controlled trial comparing early palliative care integrated with standard oncology care versus standard oncology care alone at Massachusetts General Hospital.³¹ We enrolled eligible patients within 8 weeks after diagnosis and randomly assigned them in a 1:1 fashion without stratification. Participants completed baseline measures before random assignment and notification of study arm allocation. Patients assigned to the intervention group met with a member of the palliative care team, which consisted of board-certified palliative care physicians and advanced-practice nurses, within 3 weeks of enrollment and at least monthly thereafter in the outpatient setting until death. Members of the care team and patients could schedule additional visits with the palliative care service at their discretion.

The study protocol included general guidelines for the ambulatory palliative care visits, which we adapted from the National Consensus Project for Quality Palliative Care.²³ Specifically, the palliative care clinicians addressed

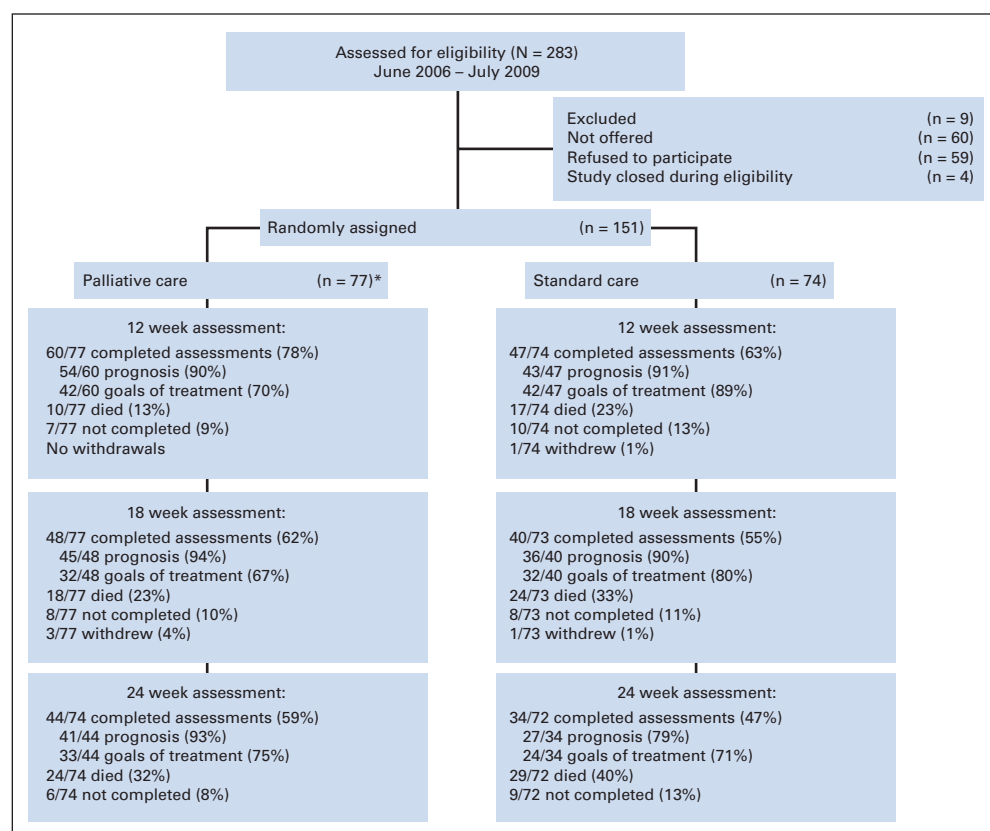


Fig 1. CONSORT diagram. *One patient randomly assigned to standard care was erroneously assigned to early palliative care at the time of random assignment and therefore is included in the early palliative care study group.

the following aspects of care with study patients: illness understanding and education; symptom management; treatment decision making; coping with a life-threatening illness for patients and families; and development of care plans for future appointments and referrals to other care providers. Participants randomly assigned to the standard care group only met with the palliative care service on request from the patient, family, or oncologist, though these participants did not crossover to the palliative care group or follow the specified palliative care protocol. Regardless of group assignment, all participants continued to receive standard oncology care throughout the study period. The Dana Farber/Partners Cancer Care institutional review board approved the study protocol, and all participants provided written informed consent.

Patient Selection

Patients who presented to the outpatient thoracic oncology clinic were eligible to enroll if they had pathologically confirmed metastatic NSCLC diagnosed within the previous 8 weeks, an Eastern Cooperative Oncology Group (ECOG) performance status of 0 to 2, and the ability to read and respond to questions in English. Patients who were already receiving consultation from the palliative care service were not eligible to participate. All medical oncologists in the clinic agreed to recruit and obtain consent from their patients.

Patient-Reported Measures

Illness perceptions. To assess perceptions of prognosis and goals of therapy, we adapted and modified the following two self-report items, which have been used in previous studies of patients with advanced cancer^{32,33}: “My cancer is curable” (yes/no); and “The goals of my therapy are to “help me live longer” (yes/no), “try to make me feel better (yes/no), or “get rid of all my cancer” (yes/no).

Data Collection

Participants completed baseline questionnaires before random assignment. We administered the follow-up assessments at 12, 18, and 24 weeks (or at a clinic visit within 3 weeks of that time). Participants who had no scheduled clinic visits during this time frame received the questionnaires by mail.

We also recorded the dates of chemotherapy utilization from participant electronic medical records. Specifically, we collected the date of the last chemotherapy administration to determine if participants received intravenous infusions within 60 days of death.

Statistical Analyses

We performed statistical analyses by using SPSS (version 17.0; SPSS, Chicago, IL). Analyses began with descriptive summaries of demographic and clinical variables. Given that participant response rates varied by item, we present the denominator for each variable. We examined bivariate associations with two-sided χ^2 and Fisher's exact tests for categorical variables and independent-samples *t* test for continuous variables.

RESULTS

Patient Characteristics

From June 2006 to July 2009, 283 eligible patients presented to the thoracic oncology clinic, and 151 patients (53%) enrolled on the study (CONSORT diagram; Fig 1). Patient demographic factors did not differ significantly between study participants and eligible patients who did not enroll (data not shown). Baseline characteristics as well as perceptions of prognosis and goals of therapy were well matched between the participants randomly assigned to early palliative care versus standard care (Table 1).

Baseline Illness Perceptions

Across study groups, almost one third of patients (46 [31.7%] of 145 patients) reported that their cancer was curable at baseline (Fig 2). Although nearly all patients indicated that the goals of therapy were to help them live longer (138 [97.2%] of 142 patients) and try to make them feel better (128 [100%] of 128 patients), the

Table 1. Baseline Demographic and Clinical Characteristics

Variable	Standard Care (n = 74)		Early Palliative Care (n = 77)		P*
	No.	%	No.	%	
Age, years					.94
Mean	64.87		64.98		
SD	9.4		9.7		
Sex					.52
Female	36	48.6	42	54.5	
Race/ethnicity					.06†
White	70	94.6	77	100.0	
Black	3	4.0	0	0.0	
Asian	1	1.4	0	0.0	
Hispanic/Latino ethnicity	1	1.4	1	1.3	1.00
Marital status					1.00
Married	45	60.8	48	62.3	
Single	9	12.2	9	11.7	
Divorced/separated	12	16.2	12	15.6	
Widowed	8	10.8	8	10.4	
ECOG PS‡					.24
0	30	40.5	26	33.8	
1	35	47.3	46	59.7	
2	9	12.2	5	6.5	
Initial anti-cancer therapy					.87§
Platinum-based combined chemotherapy	35	47.3	35	45.5	
Single agent	3	4.1	9	11.7	
Oral EGFR-TKI	6	8.1	6	7.8	
Radiation	26	35.1	27	35.1	
Combined chemoradiotherapy	3	4.1	0	0.0	
No treatment	1	1.4	0	0.0	
Illness perceptions					
Cancer curable	23 of 71	32.4	23 of 74	31.1	1.00
Goals of therapy					
Help me live longer	66 of 68	97.1	72 of 74	97.3	1.00
Try to make me feel better	64 of 64	100.0	64 of 64	100.0	
Get rid of all of my cancer	41 of 60	68.3	45 of 64	70.3	.85

Abbreviations: SD, standard deviation; ECOG, Eastern Cooperative Oncology Group; PS, performance status; EGFR, epidermal growth factor receptor; TKI, tyrosine kinase inhibitor.

*P values were derived from two-sided χ^2 and Fisher's exact tests for categorical variables and from the independent-samples *t* test for continuous variables.

†Fisher's exact test comparing rates of white patients versus patients in a minority group (ie, black and Asian) by condition.

‡An ECOG PS of 0 indicates that the patient is asymptomatic; 1, that the patient is symptomatic but fully ambulatory; and 2, that the patient is symptomatic and in bed less than 50% of the day.

§Fisher's exact test comparing rates of platinum-based combination chemotherapy versus other treatment by condition.

majority (86 [69.4%] of 124 patients) also reported that a goal of therapy was to get rid of all their cancer. To additionally elucidate patient perception of illness, we examined the agreement between the following two items: my cancer is curable, and the goals of my therapy are to get rid of all of my cancer. As shown in Figure 2, although two thirds of patients answered in a concordant fashion (ie, yes or no to both questions); approximately one third of patients responded differently to these two items. Most of the patients with discordant answers (40 [95.2%] of 42 patients) reported that their cancer was not curable but still believed that the goal of therapy was to get rid of all of their cancer.

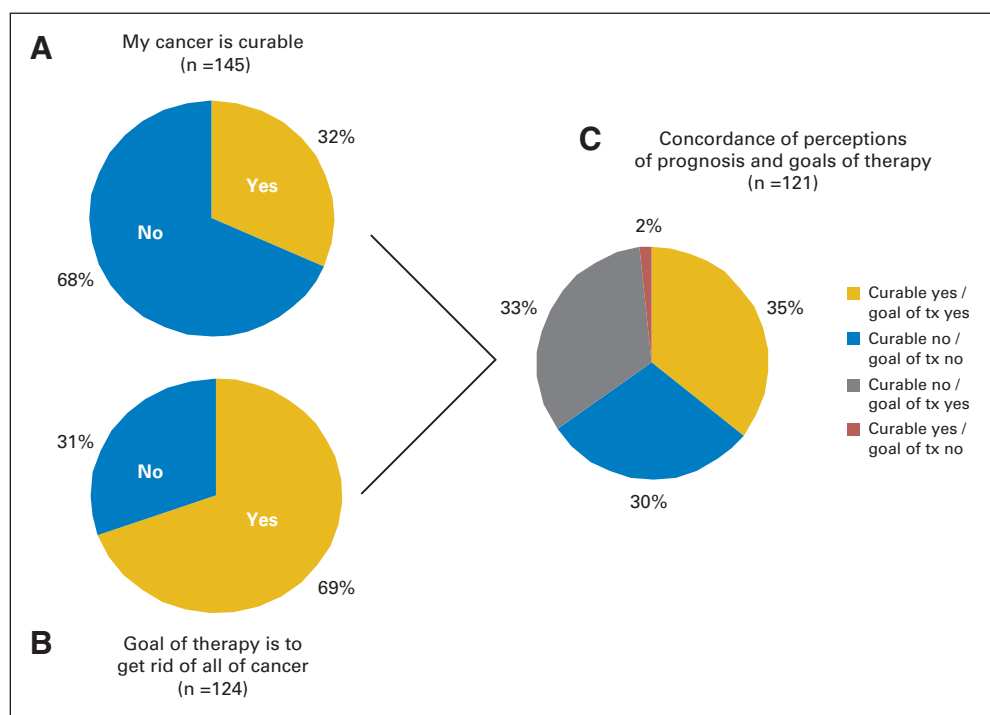


Fig 2. Baseline perceptions of prognosis and goals of treatment. (A) Results of the 145 patients who responded to the question, "My cancer is curable (yes/no)." (B) Results of the 124 patients who responded to the question, "The goal of my therapy is to get rid of all of my cancer (yes/no)." (C) Results of the 121 patients who responded to both questions. tx, therapy.

Palliative Care Visits

Patients randomly assigned to standard oncology care were permitted to consult with the palliative care team on request at any point during the study period. Table 2 details the median number of palliative care visits for each study group at the three follow-up time points. All patients assigned to early palliative care, except for one who died within 2 weeks of enrollment, had at least one visit with the palliative care team by week 12. In contrast, only 10 patients (13.5%) in the standard care group had a palliative care consultation in the first 12 weeks of the study, primarily for symptom management. By week 24, the median number of palliative care visits was 0 (range, 0 to 5) for patients assigned to standard care, and it was 7 (range, 0 to 14) for those in the early palliative care group, which confirmed infrequent early referral to palliative care for participants in the standard care arm.

Effect of Early Palliative Care on Longitudinal Perceptions of Illness Understanding

The CONSORT diagram (Fig 1) includes completion rates for the study questionnaires at each point of assessment. Because some patients did not answer all of the illness perceptions questions, we

included the number who responded to each item on the CONSORT as well as the numerator and denominator for each item in the tables. A greater percentage of patients assigned to standard care reported their cancer to be curable at 12 weeks compared with patients in the early palliative care group (17 [39.5%] of 43 patients v 12 [22.2%] of 54 patients; $P = .08$). This difference persisted at 18 weeks (13 [36.1%] of 36 patients v eight [17.8%] of 45 patients; $P = .08$), although the percentages between groups by 24 weeks were more similar (Table 3). Patient perceptions of the goals of treatment did not differ significantly between study groups at any time point, and the majority of patients continued to report that an aim of therapy was to get rid of all the cancer. Similar to the baseline assessment, most patients in both groups reported at 12, 18, and 24 weeks that the goals of therapy were to help them live longer and to try to make them feel better (data not shown).

To determine the effect of early palliative care on illness understanding by patients over time, we examined whether participants remained or became accurate in their perceptions of prognoses (ie, curability) and goals of therapy. Patients who completed at least two self-report assessments across the four study time points were included in these analyses. We considered participants who consistently

Table 2. Palliative Care Visits by Study Group From Baseline to 12, 18, and 24 Weeks

Study Time Point	Standard Care (n = 74)				Early Palliative Care (n = 77)			
	No. With PC Visits	%	Median	Range	No. With PC Visits	%	Median	Range
12-week	10	13.5	0	0-2	76	98.7	4	0-8
18-week	12	16.2	0	0-4	76	98.7	5	0-11
24-week	15	20.3	0	0-5	76	98.7	7	0-14

NOTE. No. with PC visits refers to the No. of patients who received any palliative care (PC) visits by each time point. Median refers to the average No. of PC visits for all participants within each study group by each time point. Range refers to the minimum and maximum No. of PC visits for all participants within each study group by each time point.

Table 3. Illness Understanding by Study Group at Weeks 12, 18, and 24

Illness-Understanding Variable	Standard Care			Early Palliative Care			P*
	No.	Total No.	%	No.	Total No.	%	
Cancer is curable†							
12-week	17	43	39.5	12	54	22.2	.08
18-week	13	36	36.1	8	45	17.8	.08
24-week	8	27	29.6	9	41	22.0	.57
Goal to rid all cancer‡							
12-week	33	42	78.6	26	42	61.9	.15
18-week	21	32	65.6	17	32	53.1	.45
24-week	14	24	58.3	19	33	57.6	1.00

*P values were derived from two-sided Fisher's exact tests.

†Numbers and percentages in table refer to those participants who reported yes to the statement, "My cancer is curable."

‡Numbers and percentages in table refer to those participants who reported yes to the statement: The goal of my therapy is "to get rid of all my cancer."

reported that their cancer was not curable across time as remaining accurate, and we categorized those who initially reported that their cancer was curable and then changed this response to the negative on subsequent assessments as becoming accurate. During the 6-month study period, a greater percentage of patients assigned to early palliative care either remained or became accurate in the perception that the cancer was not curable compared with patients receiving standard care (47 [82.5%] of 57 patients v 28 [59.6%] of 47 patients; $P = .02$; Fig 3A). We used the same method to categorize patient views on the goals of therapy over time and observed that the two study groups did not differ significantly in their reports of whether a goal of therapy was to get rid of all their cancers. Specifically, although more patients assigned to early palliative care versus those receiving standard care remained or became accurate in their belief that a goal of therapy was not to get rid of all cancer (21 [43.8%] of 48 patients v 14 [31.8%] of 44

patients), this difference failed to meet the threshold for statistical significance ($P = .29$; Fig 3B).

Perceptions of Prognosis and Chemotherapy Administration Near the End of Life

We examined whether changes in perceptions of prognoses were associated with the administration of chemotherapy near the end of life. Within the early palliative group, the percentage of patients receiving intravenous chemotherapy within 60 days of death was significantly lower among those who remained or became accurate over time in their view of prognoses compared with those who maintained inaccurate perceptions (three [9.4%] of 32 patients v four [50%] of eight patients; $P = .02$; Fig 4). Within the standard-care group, the percentage of patients receiving chemotherapy did not differ according to changes in perceptions of prognosis over the 6-month study period.

DISCUSSION

As the first clinical trial, to our knowledge, to demonstrate improvements in illness perceptions, our study shows that patients with metastatic NSCLC assigned to early palliative care were significantly more likely to retain or develop an accurate view of their prognoses compared with patients receiving standard oncology care. We and others have previously observed that palliative care is beneficial for a variety of patient outcomes, including quality of life, mood, and symptom burden.^{24,27,31} In addition to a focus on physical and psychological symptoms, the Clinical Practice Guidelines for Quality Palliative Care charge palliative care teams to improve the processes of care through education and enhanced communication regarding goals of care.²³ However, evidence that integration of palliative care services throughout the course of disease can alter patient perceptions of illness has been lacking to date. The findings of the present study not only

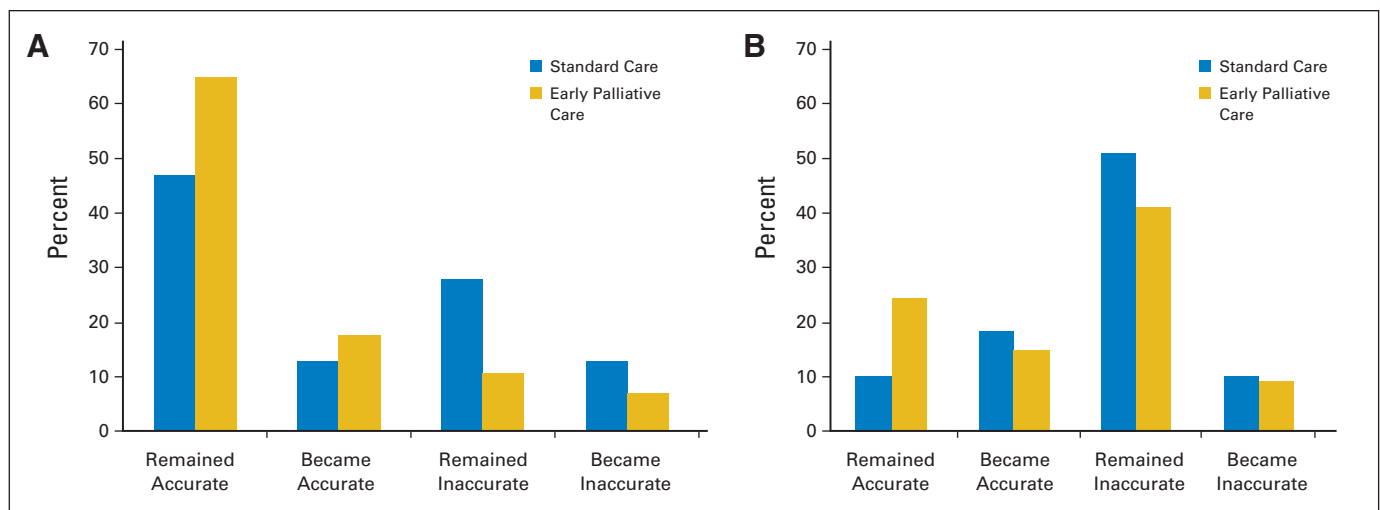


Fig 3. Changes in perceptions of prognosis and goals of treatment. (A) Of the 104 participants with completed self-report assessments across a minimum of two study time points, those assigned to early palliative care were more likely than those receiving standard care to remain or become accurate in their perceptions that their cancers were not curable (early palliative care, 47 [82.5%] of 57 patients; standard care, 28 [59.6%] of 47 patients; Fisher's exact test for comparison, $P = .02$). (B) Of the 92 participants with completed self-report assessments across a minimum of two study time points, a greater percentage of patients assigned to early palliative care remained or became accurate in their belief that a goal of therapy was not to get rid of all the cancer, though the difference was not significant (early palliative care, 21 [43.8%] of 48 patients; standard care, 14 [31.8%] of 44 patients; Fisher's exact test for comparison, $P = .29$).

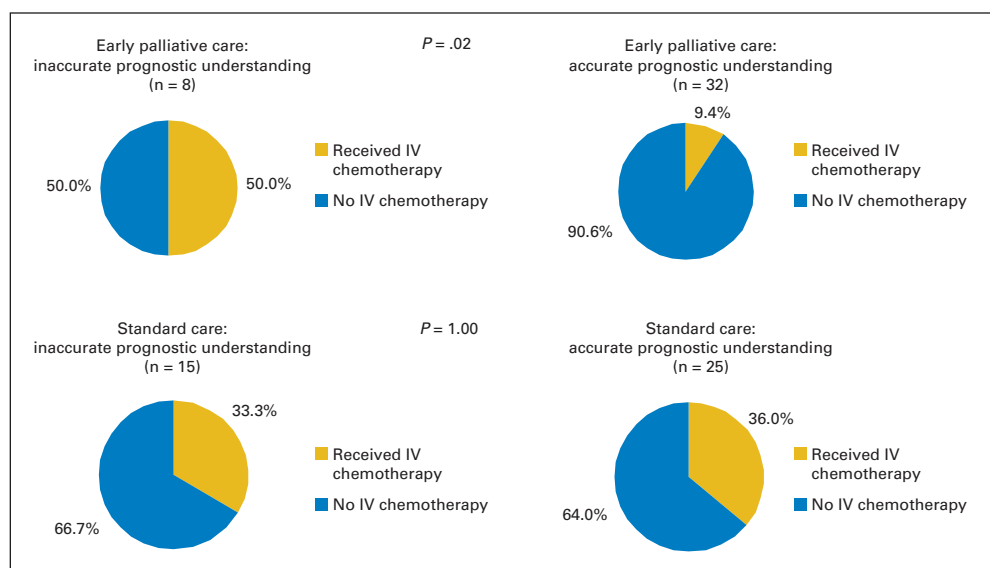


Fig 4. Chemotherapy near the end of life according to study arm and prognostic understanding. Sample size for this subgroup analysis was 80 patients, which represents the number of patients who had died by the time of analysis and had follow-up data on prognostic understanding and chemotherapy utilization. With early palliative care: percentage of patients with an accurate prognostic understanding (three [9.4%] of 32 patients) versus inaccurate prognostic understanding (four [50%] of eight patients) receiving intravenous (IV) chemotherapy within 60 days of death (Fisher's exact test, $P = .02$). With standard care: percentage of patients with an accurate prognostic understanding (nine [36.0%] of 25 patients) versus inaccurate prognostic understanding (five [33.3%] of 15 patients) receiving IV chemotherapy within 60 days of death (Fisher's exact test, $P = 1.00$).

highlight that early palliative care clarifies patient understanding of prognosis but also indicate that change in these perceptions over time is significantly associated with decisions regarding care near the end of life.

Almost one third of the participants in our trial reported that their cancer was curable at baseline; the majority also endorsed the belief that treatment could eliminate their cancer, despite enrollment on a randomized study of palliative care. Interestingly, 33% of participants had discordant illness perceptions, noting that their cancers were incurable while simultaneously indicating that the goal of therapy was to get rid of all of their cancers. Such conflicting views may be due to confusion about the nature of anticancer therapy, in which patients understand that their cancer is incurable but nonetheless hope that chemotherapy will lead to complete remission. This misperception is concerning, as complete responses to chemotherapy are exceedingly rare among those with metastatic NSCLC.³⁴⁻³⁶ A key component of the informed consent process in oncology includes a detailed discussion of the risks and benefits of treatment. Our data suggest either that patients are failing to appreciate the oncologist treatment recommendations or that clinicians are not providing adequate information regarding the goals of therapy.³⁷ In either case, patients who misunderstand the expected outcomes of cancer therapy may elect for treatments they would have otherwise declined.^{7,37,38}

Patients receiving early palliative care were significantly more likely to report an accurate assessment of their prognosis over time, and such improvement in prognostic understanding was associated with treatment decisions at the end of life. Specifically, patients assigned to early palliative care who had an accurate understanding of their prognoses were significantly less likely to receive chemotherapy near the end of life. In contrast, accuracy in prognostic understanding was not associated with the receipt of chemotherapy for patients receiving standard care. The provision of palliative care in this trial did not follow a script or schedule for discussing prespecified topics. Rather, clinicians had the flexibility to provide patient-centered care tailored to the specific needs of patients at each clinic visit. Because this study was structured as a novel model of integrated care, rather than a prescribed intervention, we are unable to ascribe a specific process that

led to the improvements in perceptions of prognosis. However, a primary focus of the standard practice of palliative care entails educating patients regarding their illnesses and prognoses to enable informed decision making.²³ The utility of early palliative care did not extend to patient views regarding the goals of treatment. Future interventions may be strengthened by joint oncology and palliative care consultations to ensure that patients hold a clear and accurate understanding of the goals of therapy.

A main study limitation is that no scale exists to assess the multidimensional construct of illness understanding in patients with metastatic cancer. We therefore adapted items from previously published research. Some patients did not answer all questions and most often left blank the item stating, the "goal of therapy is to get rid of all my cancer," suggesting that the wording may have been difficult to interpret. Yet, the fact that the majority of participants endorsed this item as a goal of therapy is notable, especially for a patient population in which the probability of even a partial response to second-line chemotherapy is less than 10%.³⁹ However, the degree of missing data on this item may have limited our ability to detect statistically significant differences between the two groups. To address the need for validated assessment tools, we are now conducting research to evaluate illness understanding more comprehensively in patients with metastatic NSCLC by using a modified version of questionnaires developed and validated for parents of children with cancer by Mack et al.⁴⁰⁻⁴²

Many patients with metastatic NSCLC have inaccurate views of their prognoses and the goals of cancer therapy. These misperceptions not only place patients at risk for making unsuitable choices for their care but also have salient societal implications, as they may lead patients to opt for futile, burdensome, and costly therapies at the end of life. We demonstrate that integrated and longitudinal palliative care, beginning near the time of diagnosis, can significantly improve patient knowledge of prognosis over time. In addition, patients receiving early palliative care who have more accurate perceptions of their prognoses are less likely to receive chemotherapy near the end of life. This notable finding adds to our previous data demonstrating the benefits of early palliative care with respect to quality of life, mood, and survival and provides additional compelling evidence for integrating these services

earlier in the course of disease. Additional study on the role of early palliative care in other advanced cancer populations and care settings, including multisite trials, is clearly warranted.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Although all authors completed the disclosure declaration, the following author(s) indicated a financial or other interest that is relevant to the subject matter under consideration in this article. Certain relationships marked with a "U" are those for which no compensation was received; those relationships marked with a "C" were compensated. For a detailed description of the disclosure categories, or for more information about ASCO's conflict of interest policy, please refer to the Author Disclosure Declaration and the Disclosures of Potential Conflicts of Interest section in Information for Contributors.

AUTHOR CONTRIBUTIONS

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Manuscript writing: All authors

Final approval of manuscript: All authors

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