

Offering Chemotherapy and Hospice Jointly: One Solution to Hospice Underuse

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Purpose. Patients with advanced lung cancer typically receive chemotherapy at the cost of receiving care that may promote quality of life more effectively. The authors examined whether offering chemotherapy and hospice concurrently, a clinically appropriate but often unavailable option, might resolve this problem. **Method.** Adult smokers (N = 198) completed an Internet-based survey in which they imagined having advanced lung cancer. Participants rated the effectiveness of 4 treatments (supportive care alone, chemotherapy with supportive care, hospice, and chemotherapy with hospice) at achieving 4 goals of treatment (extending survival, controlling symptoms, avoiding side effects, and promoting quality of life at the end of life). **Results.** Reflecting utilization patterns of lung cancer patients, few respondents preferred supportive care alone (10%) or hospice (19%), and many preferred chemotherapy (29%). The most common choice was concurrent chemotherapy and hospice (42%).

Treatments that involved chemotherapy were seen as the most effective at extending survival, whereas treatments that involved hospice were seen as most effective at promoting quality of life. Effectiveness ratings were weakly related to preferences for hospice, moderately related to preferences for chemotherapy with supportive care, and strongly related to preferences for chemotherapy and hospice together. **Conclusions.** These findings suggest that interest in hospice may be low because, offered without chemotherapy, hospice is perceived as ineffective at controlling symptoms and avoiding side effects. Chemotherapy and hospice together may be a preferred option for treating advanced lung cancer. Furthermore, preferences for chemotherapy and hospice together best reflect the values people placed on the goals of treatment. **Key words:** lung cancer; hospice; chemotherapy; preferences; end of life; decision making. (*Med Decis Making* 2009;29:521-531)

Lung cancer is the leading cause of cancer deaths in the United States. An estimated 161,840 Americans died this disease in 2008.¹ Most people with lung cancer are diagnosed with non-small-cell lung cancer (NSCLC), and 39% of NSCLC patients are diagnosed at an advanced and inoperable stage.²

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Patients with advanced NSCLC cannot be cured of their disease, but treatments available to them offer some combination of extension of survival, palliation of symptoms (which may improve quality of life), and preparation for dying. All patients receive a baseline of supportive care to palliate their symptoms. In addition, patients may opt for chemotherapy, hospice, or hospice with chemotherapy. These approaches differ in their primary goals. Supportive care alone aims to palliate symptoms of the disease without providing chemotherapy. Chemotherapy treatments target tumors to prolong survival and reduce symptom occurrence, although it is often accompanied by unpleasant side effects that require palliation. Hospice palliates symptoms within the context of a multidisciplinary approach to help patients and their families cope with the dying process and bereavement.

Few patients use hospice care, and advocates of hospice consider it vastly underused.³⁻⁵ Patients with advanced lung cancer typically receive aggressive therapies, such as chemotherapy, at the end of life.^{6,7}

Hospice care offers palliative care and support at the end of life. Unfortunately, only about 21% of lung cancer patients enroll in hospice, and these patients enroll in hospice quite late.⁸ Although hospice is designed for a minimum 3-month stay, and most physicians endorse a 3-month stay, the lung cancer patients who do use hospice care have a median stay of 38 days, with about 15% of patients dying within a week of entry into hospice.⁸⁻¹⁰ The American College of Chest Physicians (ACCP) expressed concern over the pattern of “repeated episodes of short-term, life-prolonging efforts, followed in the last weeks by a short period of end-of-life care in hospice or another setting.”¹¹

Why are so few lung cancer patients using hospice? The simplest explanation is that clinicians present the option to patients too late or not at all, but there are likely to be many other important reasons. One possibility is that patients prefer aggressive treatment when forced to choose between hospice and chemotherapy. Studies of preferences among cancer patients have shown that although some patients value quality of life over survival,¹²⁻¹⁵ other patients value living as long as possible,¹⁶⁻¹⁸ which is not a goal of hospice. If patients and their families equate hospice with giving up, they may avoid enrolling in hospice care.^{3,19}

A related explanation for hospice underuse is that patients who want to continue receiving aggressive care often cannot do so in the context of hospice. Offering chemotherapy in the context of hospice care is increasingly medically acceptable, but it is often unavailable. Medical insurance typically does not offer enough reimbursement to cover both aggressive therapies and hospice when delivered simultaneously.²⁰⁻²² In addition, hospices often resist admitting patients undergoing aggressive treatments on the philosophical grounds that aggressive treatment is antithetical to the goal of prioritizing quality of life during the last stage of life.³ However, some patients leave hospice to pursue aggressive treatments that would not be covered under the hospice guidelines, suggesting that prohibiting chemotherapy within hospice care is undesirable to some patients.²³ By making concurrent chemotherapy and hospice available, patients could enter hospice sooner and take advantage of its many palliative and psychosocial services. Offering simultaneous palliative services and chemotherapy fits well into models of integrated end-of-life care.^{20,24} Indeed, insurers and hospices that allow “open-access hospice” have facilitated earlier

entry into hospice by allowing patients to receive more aggressive therapies while in hospice care.^{5,19}

The ACCP guidelines for palliative treatment of lung cancer state the importance of improving the “congruence of treatment with goals and preferences of the patient.”¹¹ However, our understanding of lung cancer patient preferences at the end of life is incomplete. Studies of patient preferences for NSCLC treatment have not included the option of hospice care, but have simply compared aggressive therapies with supportive care.^{11,14,15,25} Further, no studies have investigated preferences for concurrent hospice and chemotherapy. Thus, we do not have enough information to know whether patients would want concurrent chemotherapy and hospice care.

One way to address this question is to ask people explicitly what they would be likely to choose if they were facing this treatment decision (i.e., what they say they would want). Another method is to infer preferences through a multiattribute utility analysis, which requires separately assessing each treatment option along the most relevant dimensions (i.e., what would maximize their utility). Multiattribute utility theory (MAUT) is the normative standard for choosing between multiple options.²⁶ Based on expected utility theory, MAUT posits that people will derive the most benefit from choosing options expected to give the most utility on attributes that they give more weight. Thus, MAUT analysis incorporates utilities people have provided for different attributes of a decision, weighting them by the importance people place on each attribute. MAUT analysis has been used to understand preferences in numerous medical contexts including prostate cancer and head and neck cancer.²⁷⁻³⁰ In trying to understand why hospice is underused, the distributed nature of MAUT analysis could allow preferences for hospice to emerge because the analysis does not force participants to choose explicitly this potentially emotionally laden care option.

In this study, we examined 2 questions about treatment of advanced lung cancer: First, can the low rate of hospice use be explained by a simple preference for more aggressive care? Second, if offered chemotherapy in the setting of hospice care, would this increase people’s interest in hospice? To answer these questions, we probed how beliefs about treatment for advanced stage lung cancer affected their treatment preferences. We also sought to understand better how people’s choices compared with a less aggregated approach using MAUT analysis.

Table 1 Goals of Treatment for Advanced NSCLC

Goals of Treatment	Treatment Options			
	Supportive Care Alone	Chemotherapy with Supportive Care	Hospice	Chemotherapy with Hospice
Extension of survival	Does not extend survival	May extend survival by a mean of 2.5 months	Does not extend survival	May extend survival by a mean of 2.5 months
Palliation of symptoms	Palliates by targeting symptoms	Palliates by targeting cancer and symptoms	Palliates by targeting symptoms	Palliates by targeting cancer and symptoms
Avoiding side effects/toxicity	Does not have side effects	May cause side effects such as fatigue, hair loss, and nausea. Supportive care tries to alleviate these side effects.	Does not have side effects	May cause side effects, like fatigue, hair loss, and nausea. Hospice care tries to alleviate these side effects.
Promotion of quality of life at the end of life	No added services	No added services	Offers psychological, spiritual, and practical support at the end of life	Offers psychological, spiritual, and practical support at the end of life

Note: NSCLC, non-small-cell lung cancer.

METHODS

Participants

We explored these issues with a proxy population of adult smokers because current and former smokers comprise 90% of lung cancer cases.³¹ Furthermore, because smokers typically believe they are at high risk for lung cancer, they may find the lung cancer-related topics in the survey more engaging.^{32,33} We recruited adult smokers using an advertisement emailed to university staff and students. We assessed smoking status using a validated item from the California Tobacco Survey, “Do you smoke cigarettes?”³⁴ Response options were “every day,” “some days,” or “not at all”; respondents who selected “some days” or “every day” were deemed eligible to participate.

Procedure

We asked participants to imagine facing a decision about treatment for incurable lung cancer (Appendix A). They then read descriptions of 4 treatment options that varied on whether they involved chemotherapy or hospice (Appendix B). We used plain language in the survey and pilot-tested the survey with 10 patients with advanced lung cancer. Participants received \$10 for completing a 15-min online questionnaire at their convenience. The University of North Carolina’s institutional review board reviewed and approved the study protocol.

Measures

A review of the literature on concerns of patients with advanced cancers identified 4 goals of treatment most relevant to patients with incurable NSCLC: extension of survival, palliation of symptoms, avoidance or reduction of side effects, and promotion of the quality of life at the end of life.^{12,14,15,25,35–37} A description of the treatment options and their performance at achieving each goal appears in Table 1.

Participants rated how effectively each treatment option achieved the goals of treatment on a 5-point response scale labeled from “not effective at all” to “very effective.” These were the effectiveness measures. Participants also ranked the importance of the 4 goals of treatment in making this decision, forming the goal rank measures.

Participants’ attitudes toward the treatment options were assessed 3 ways. First, they were asked to rate how likely they would be to choose each treatment option, on a 5-point response scale ranging from “very unlikely” to “very likely.” These formed the 4 intention measures. Second, participants were asked which treatment option they would be most likely to choose, which formed the choice measure. Multiattribute utility analysis combined effectiveness ratings and goal rankings to identify the top-ranked choice implied by their ratings. Goal rankings were converted to weights using the Edwards and Barron method.³⁸ Each of the 4

effectiveness measures of a treatment option were multiplied by its corresponding weight to generate 4 weighted effectiveness measures. The weighted effectiveness measures were summed to generate a single overall utility score for each treatment option as shown in the equation below.

$$utility = \sum_{k=1}^4 weight_k * effectiveness_k$$

The treatment option with the highest overall utility became the MAUT-identified choice.

Data Analysis

Statistical analyses were performed using Stata 10 (Statacorp, College Station, TX). Missing data for independent variables for 9 participants were replaced using a multiple imputation procedure in Stata (*ice*).³⁹⁻⁴¹ The pattern of results was the same when these were excluded from the analysis. Effectiveness ratings for each goal of treatment were compared using analyses of variance and post-hoc paired *t* tests. Concordance between outcomes of MAUT analyses and choice items were assessed using the κ statistic. All analyses were 2-tailed with a critical α of 0.05, except for the post-hoc *t* tests, which had a 2-tailed critical α of 0.01 to correct for multiple comparisons. Because Bonferroni corrections for multiple post-hoc tests did not affect our findings, we do not report them for the sake of simplicity.

Four ordered logit models were used to model intention, 1 for each treatment option. The models predicted the influence of effectiveness ratings on the intention to choose each treatment, controlling for age, gender, race, ethnicity, marital status, and level of education. The results are reported using standardized regression coefficients (β values). Percentage of variance explained was assessed using McKelvey and Zavoina's R^2 for ordered logit models.⁴²

RESULTS

Of 227 adult smokers who consented to take the survey, 198 completed the survey (87% completion rate). The mean age was 34 (SD = 12); 76% were white, and 82% had at least some college education; 43% were never married, and 41% were married or living with a partner; 85% had a close friend or family member with cancer (Table 2).

When asked to rank the goals of treatment, the most commonly top-ranked goal was promoting

Table 2 Characteristics of Study Participants

	Mean (SD)
Age (in years)	34 (12)
	<i>n</i> (%)
Gender	
Male	78 (39)
Female	114 (58)
Race	
White	151 (76)
Black	24 (12)
Other	22 (11)
Hispanic	6 (3)
Education	
High school graduate or less	17 (9)
Technical, trade, business	19 (10)
Some college	78 (39)
College graduate or more	84 (43)
Marital status	
Married or living with partner	83 (42)
Widowed, divorced, or separated	29 (15)
Never married	85 (43)
Friend or family member has had cancer	
Yes	167 (85)
No	30 (15)

Note: Observations may not sum to 100% because of missing data.

quality of life at the end of life (41%), followed by extending survival (33%). Palliating symptoms was ranked highest by 18% of participants, and avoiding side effects of treatment was least commonly rated highest (8%).

When participants were asked to select only 1 treatment option, the most frequently selected option was concurrent chemotherapy and hospice care (42%, 83 of 198). Chemotherapy with hospice was followed by chemotherapy with supportive care (29%, 57 of 198), hospice (19%, 38 of 198), and supportive care alone (10%, 20 of 198). A similar pattern was seen when participants rated their intention of choosing each treatment option (Figure 1).

The multiattribute utility analysis generated a single best choice (the choice with the highest summed score) for each participant, except in 12 cases for which there was more than 1 treatment option with the highest weighted summed utilities and 1 case for which the participant did not provide rankings ($n = 185$). Just as chemotherapy with hospice care was the most frequently chosen treatment option ($n = 83$, 42% of participants), chemotherapy with hospice care was the option most frequently generated in MAUT analysis ($n = 87$, 44% of participants). This option was followed by hospice care

Table 3 Concordance of Choice with MAUT-Yielded Option

Choice	MAUT-Yielded Option					Total, <i>n</i>
	Supportive Care Alone, <i>n</i> (%)	Chemotherapy with Supportive Care, <i>n</i> (%)	Hospice, <i>n</i> (%)	Chemotherapy with Hospice, <i>n</i> (%)	Ties (No Option Yielded), <i>n</i> (%)	
Supportive care alone	5 (17)	3 (13)	7 (16)	4 (5)	1 (8)	20
Chemotherapy with supportive care	10 (33)	10 (42)	7 (16)	28 (32)	2 (15)	57
Hospice	8 (27)	1 (4)	18 (41)	5 (6)	6 (46)	38
Chemotherapy with hospice	7 (23)	10 (42)	12 (27)	50 (57)	4 (31)	83
Total	30 (100)	24 (100)	44 (100)	87 (100)	13 (100)	198

Note: MAUT, multiattribute utility theory. Bold numbers indicate concordant pairs.

($n=44$, 22% of participants), supportive care alone ($n=30$, 15% of participants), and chemotherapy with supportive care ($n=24$, 12% of participants) (Table 3).

Concordance between choice and MAUT-identified choice was low overall ($\kappa=0.22$, $P < 0.05$) (Table 3). Simple agreement was highest for chemotherapy with hospice; 57% (50 of 87) of people who chose chemotherapy with hospice had preferences consistent with this choice, according to the MAUT analysis. The lowest agreement was for supportive care (17%, 5 of 30). Agreement about hospice was at an intermediate level. One source of the low agreement overall was 28 people who chose chemotherapy, but whose preferences were more consistent with chemotherapy and hospice together.

Participants evaluated the effectiveness of the 4 treatment options at achieving the 4 goals of treatment (Figure 2). The 4 treatments received significantly different effectiveness ratings for each of the treatment goals (extending survival, palliating symptoms, avoiding side effects, and promoting quality of life at the end of; $F_{3,197} > 20$, $P < 0.05$).

Within each goal of treatment, post-hoc t tests showed that effectiveness measures for each treatment were significantly different from each other in all but 3 cases (Figure 2). Extending survival was seen as best achieved with treatments that involved chemotherapy (with or without hospice care). Promoting quality of life at the end of life was seen as best achieved with treatments that involved hospice (with or without chemotherapy). The treatments were less distinguishable in their perceived ability to control symptoms or avoid side effects. Interestingly, on average, supportive care was rated more effective than hospice at extending survival ($t_{197} = 8.98$, $P < 0.05$), controlling symptoms ($t_{197} = 13.41$,

$P < 0.05$), and avoiding side effects ($t_{197} = 10.94$, $P < 0.05$).

The perceived effectiveness of supportive care at achieving any of the 4 goals of treatment was not associated with intentions to choose supportive care (Table 4). However, the perceived effectiveness of chemotherapy with supportive care at extending survival ($\beta=0.13$) and promoting quality of life at the end of life ($\beta=0.17$) was associated with intentions to choose that treatment.

Hospice care's effectiveness at extending survival ($\beta=0.12$) and promoting quality of life at the end of life ($\beta=0.15$) were both statistically significantly associated with increases in intention to use hospice care.

For concurrent chemotherapy and hospice care, perceived effectiveness at promoting quality of life at the end of life ($\beta=0.24$) was positively associated with intentions to choose this treatment option.

These statistically significant associations indicate that these goals matter when selecting among treatment options. Perhaps more telling is the percentage of variance explained by each model. The effectiveness ratings of supportive care alone are the poorest predictors of intentions to have this treatment, explaining only 3% of the variability. The low R^2 suggests that the effectiveness of supportive care at achieving these 4 goals does not fully explain intentions to choose supportive care alone. In contrast, the effectiveness ratings of concurrent chemotherapy and hospice care explain more of the variance in predicting intentions to use this treatment ($R^2 = 0.33$).

DISCUSSION

A minority of people with advanced NSCLC enter hospice care. A possible barrier to entering hospice

Table 4 Predictors of Intentions to Choose Each Treatment Option

	Supportive Care Alone (Model 1)	Chemotherapy with Supportive Care (Model 2)	Hospice Care (Model 3)	Chemotherapy with Hospice (Model 4)
Predictors				
Extending survival	-0.06	0.13 ^a	0.12 ^a	0.06
Palliating symptoms	0.09	0.02	0.10	-0.01
Avoiding side effects	-0.06	0.07	-0.06	0.10
Promoting quality of life at the end of life	0.10	0.17 ^a	0.15 ^a	0.24 ^a
R^2	0.03	0.21	0.22	0.33

Note: Ordered logit regression models controlled for gender, age, race, ethnicity, marital status, and level of education

Regression coefficients are standardized. $N = 198$.

a. $P < 0.05$.

care is that patients often must terminate chemotherapy before entering hospice. With an increasing number of chemotherapeutic agents available for lung cancer, more patients who do not want to give up chemotherapy are likely to delay entrance to hospice.⁴³

In this proxy population of adult smokers, chemotherapy with supportive care was preferred to hospice care when assessed as intention or as a choice, mirroring utilization patterns of patients with advanced lung cancer. However, chemotherapy with hospice was the most preferred option overall, in terms of strongest intentions, most frequent choice, and most frequent elicitation by the multiattribute utility analysis. This suggests that if people are offered chemotherapy with concurrent hospice care, they may be likely to choose it, but replication with a patient population is needed before we can firmly draw this conclusion.

This finding raises the question of whether participants understood how well each treatment achieves various goals of treatment, as described to them in this study. The answer appears to be mixed. On a basic level, respondents understood that treatments involving chemotherapy were more effective at extending survival than treatments without chemotherapy. Similarly, treatments involving hospice care were understood to be more effective than other treatments at promoting the quality of life at the end of life. Further, quality of life at the end of life was the highest valued goal of treatment, suggesting that prioritizing treatments with hospice is consistent with values. However, more subtle distinctions were not as well understood. Hospice was rated less effective at allowing patients to avoid side effects and controlling symptoms than supportive care alone. This finding suggests that the goals and methods are not well understood; education of both patients and

the general public could adjust misperceptions of hospice care.

Neither the goal of symptom palliation nor the goal of avoidance of side effects factored into participants' intentions to get hospice care. Although supportive care alone and hospice both address symptoms and side effects of treatment, hospice should be considered at least as effective at these goals, if not more so, because these are explicit goals of hospice care. These inaccurate beliefs about hospice care may have made participants more reluctant to choose explicitly a treatment option that included hospice care. At the same time, they may have been rating hospice care alone and hospice with chemotherapy positively along various attributes, favoring those treatments in the MAUT analysis. This could explain, in part, the discrepancy between explicit choice and MAUT-identified choice of treatment options.

Is chemotherapy with concurrent hospice care likely to address effectively the goals of treatment that are important to people? Indeed, chemotherapy with concurrent hospice care reflects goals of treatment more strongly than other treatments. Perceived effectiveness of chemotherapy with hospice at avoiding side effects and promoting quality of life at the end of life were associated with intentions to get chemotherapy with hospice, and the 4 goals of treatment together were jointly associated with intentions to get chemotherapy with hospice. In addition, participants most frequently ranked promoting quality of life at the end of life as the most important goal of treatment (41%), followed by extending survival (33%), 2 of the main benefits of the combined chemotherapy and hospice approach. In other words, the choice of this treatment option best takes into account goals of treatment that are important to patients.

Hospice excels at promoting quality of life at the end of life, and patients and family in hospice care report high satisfaction with their care.^{21,44,45} Our study suggests that receiving chemotherapy in addition may best reflect patients' values with respect to the goals of treatment. By improving reimbursement policies and expanding the typical role of hospice to include chemotherapy, more people with advanced lung cancer could take advantage of the benefits of hospice care. In fact, the open-access movement has promoted the use of more aggressive therapies, such as chemotherapy, that could benefit patients while in hospice care.^{22,46} Similarly, palliative care services in both inpatient and outpatient settings increasingly address the palliation and psychosocial needs that are typically addressed in hospice care, and patients may continue to receive chemotherapy and other aggressive treatments.^{11,24} This service has been endorsed by the ACCP.¹¹ Future studies with patients should consider including this integrated palliative care service option in addition to concurrent chemotherapy and hospice care.

The low concordance between explicit choice of treatment options and MAUT-generated treatment choice is another interesting finding. Previous studies have noted differences in preferences when established holistically (i.e., by making a single judgment) and when disaggregated (i.e., judgments of different attributes that are then combined, for example, as in multiattribute utility analysis).⁴⁷ MAUT-identified preferences have been compared with holistic ratings (using time tradeoffs [TTO]) in the context of evaluating prostate cancer patients' health states; although the MAUT and TTO judgments were correlated, the correlation was modest ($r=0.38$).²⁹ A study using a different method of decomposing preferences (using conjoint analysis) found that explicit rankings of setting of HIV testing were similar to rankings of the settings using conjoint analysis, but they were not perfectly concordant.⁴⁸ This is consistent with research on judgment and decision making, which has shown that judgments are often more accurate when each component part is evaluated rather than making a single holistic judgment.⁴⁹ Explicit choices may be more difficult for participants, because they need to remember and integrate multiple goals of treatment into their choice, whereas techniques that summarize disaggregated ratings (such as multiattribute utility analysis) may simplify this process by breaking the choice into multiple judgments and comparisons. This suggests the superiority of disaggregated

rating processes over single judgments, as long as the disaggregation uses an exhaustive set of attributes.

This study has established that eliciting preferences for treatment and end-of-life care is feasible and yields meaningful results. However, the study has several limitations. Our sample of smokers among university staff and students may not be representative of smokers outside this academic setting. They may be more highly educated, better insured, or differ on other sociodemographic characteristics. However, the primary risk factor for lung cancer is smoking,¹ and there is no reason to believe that smokers in academic settings have a different risk of developing lung cancer than smokers outside academic settings. Another limitation of our sample is that lung cancer patients, who typically are older² and are likely less well educated than our sample, may express different preferences for treatment and end-of-life care. We did not assess health literacy, which may affect people's understanding of hospice. However, age and education were not related to preferences in this study, and education and health literacy are highly correlated.⁵⁰ Because most participants had at least some college education, however, there was limited power to detect differences at the lower levels of education. The importance people place on the attributes of treatment may be different for patients who are experiencing advanced lung cancer. Our experience has been that recruiting advanced-stage lung cancer patients into studies is difficult, and administering such a survey to lung cancer patients while at their medical appointments is more burdensome than many patients can tolerate. Further, prior studies of preferences for cancer treatments using proxy populations have added to our understanding of preferences in cancer.^{51,52} For these 3 reasons, we believe that using a proxy population is an appropriate 1st step in this research. Validating this study in a clinical setting with lung cancer patients would shed more light on preferences for treatment and end-of-life care in lung cancer.

Furthermore, the set of goals presented to participants—extending survival, controlling symptoms, avoiding side effects, and promoting the quality of life at the end of life—may have missed some of people's top priorities. For instance, a person may value the preservation of hope for a cure leading him or her to disfavor hospice care; however, our review of the literature did not identify this as a primary concern. The literature on attitudes toward end-of-life care may need to reconceptualize important attributes of care to better understand patients' experiences.

Our measures of effectiveness ratings, rankings of attributes, and treatment choices were developed from a review of the literature on lung cancer patients' preferences, but they were not tested for reliability and validity. Validation of these measures would strengthen the conclusions from this study.

Our study did not include the options of open-access hospice and integrated palliative care services, because these options were not as prominent when the study was conducted.^{5,11,19,22,46} Future studies should address these options more explicitly. A description of hospice care with a stronger focus on the goals of palliation and avoidance of side effects could improve understanding about this care option, which could, in turn, reduce discrepancies between choice and MAUT-identified options. In addition, it may be useful to probe patients' attitudes toward hospice care, to assess whether patients have negative associations with hospice that may keep them from enrolling. Finally, future studies with patients also should measure health literacy, which may affect preferences.

In sum, our study of community-dwelling smokers, the group most likely to get lung cancer, showed that chemotherapy with concurrent hospice care, an option that is often unavailable, may best suit people facing advanced lung cancer. Study findings support the conclusion of a recent editorial that argued that we need to bridge the rift between aggressive therapies and palliative care at the end of life.⁵³ In addition, a recent set of guidelines published by the National Consensus Project (NCP) for Quality Palliative Care recommended that palliative services should be integrated into patient care, starting at the time of diagnosis, easing the transition to hospice near the time of death.⁵⁴ Concurrent hospice and chemotherapy fits within this movement to enhance the continuity between aggressive and palliative therapies, and it takes advantage of the existing institution of hospice, which is both established and shown to be successful at implementing end-of-life care. Although additional work replicating our findings with lung cancer patients is needed, it may not be necessary to wait for such studies to act on our findings. Because offering concurrent hospice and chemotherapy is not inherently unethical or harmful, there is a growing movement to integrate aggressive and palliative services at the end of life, and the institutions for delivering care are already in place, policy makers may wish to revisit the issue. Expanding coverage to permit hospice within chemotherapy would reduce important cost barriers and would

allow clinicians to refer patients to a mode of care that best accords with their preferences.

APPENDIX A Description of Lung Cancer

Imaginary Situation—Advanced Lung Cancer

Please imagine having been diagnosed with advanced lung cancer, as you answer the questions on the next several pages.

Your doctor has told you that it is not possible to remove the cancer with an operation.

Your cancer cannot be cured. Your doctor has told you that you have about 6 months left to live.

You have some symptoms from the cancer, such as a persistent cough.

Any treatments you receive would be fully covered by insurance. There are 4 treatment options available to you. None of them will cure your cancer.

APPENDIX B Treatment Descriptions

Supportive Care Alone

This information will help you answer the questions on the next few pages.

What Is Supportive Care Alone?

Supportive care alone is medical care to make patients feel better. It includes pain medication, cough medication, radiation, oxygen delivery, or any treatment that is used to make patients feel better.

Everyone who has lung cancer gets supportive care from their doctor. (Some patients also get other treatments, too.)

Pros

Supportive care alone can . . .

- treat the symptoms of lung cancer, and
- avoid side effects from chemotherapy.

Cons

Supportive care alone does not . . .

- cure patients' cancer,
- make cancer tumors smaller, or
- make patients live longer.

(continued)

APPENDIX (continued)

Chemotherapy with Supportive Care

This information will help you answer the questions on the next page.

What Is Chemotherapy with Supportive Care?

Chemotherapy is medicine that may shrink or stabilize tumors. When patients get chemotherapy, they always get supportive care at the same time to make them feel as well as possible and to try to control the side effects.

Pros

Chemotherapy with supportive care . . .

- shrinks tumors or keeps them from growing in about 20% of patients,
- may help patients live about 2½ months longer,
- may prevent or lessen symptoms of lung cancer.

Cons

Chemotherapy with supportive care . . .

- causes side effects (like fatigue, hair loss, nausea, and vomiting) for most patients, but supportive care controls most of these side effects of chemotherapy.
- takes place once a week at the doctor's office to get chemotherapy. This takes a few hours each time.
- does not cure lung cancer.

Hospice Care

This information will help you answer the questions on the next page.

What Is Hospice Care?

Hospice care is care that helps patients and their families prepare for the end of life, when the time comes. It offers the same medical treatments as supportive care does, such as pain medication, cough medication, and oxygen delivery.

Hospice care aims to improve quality of life rather than to make patients live longer. It involves many types of professionals, including doctors, nurses, social workers, therapists, and spiritual advisors.

Pros

Hospice care . . .

- is provided where patients live,
- treats symptoms,
- makes patients more comfortable toward the end of life, and
- offers patients psychological, spiritual, and practical support.

Cons

Patients in hospice care must agree to not get chemotherapy or any other treatments that try to help them live longer.

Hospice care does not . . .

- cure patients' cancer,
- make cancer tumors smaller, nor
- make patients live longer.

Chemotherapy with Hospice Care

This information will help you answer the questions on the next page.

What Is Chemotherapy with Hospice Care?

Chemotherapy is medicine that may shrink or stabilize tumors. If patients get hospice care at the same time as chemotherapy, hospice care offers the same medical treatments as supportive care does, such as pain medication, cough medication, and oxygen delivery.

Hospice care aims to improve quality of life rather than to make patients live longer. It involves many types of professionals, including doctors, nurses, social workers, therapists, and spiritual advisors. Hospice care helps patients and families prepare for the end of life, when the time comes.

This option is usually not available. But we want to know how you would feel about chemotherapy with hospice care if it were available.

Pros

Chemotherapy with hospice care . . .

- is provided where patients live,
- shrinks tumors or keeps them from growing in about 20% of patients,
- may help patients live about 2½ months longer,
- treats side effects of chemotherapy and lung cancer symptoms,
- makes patients more comfortable toward the end of life, and
- helps patients with other types of care and services such as psychological, spiritual, and practical support.

Cons

Chemotherapy with hospice . . .

- does not cure patient's lung cancer
- causes side effects (like fatigue, hair loss, and nausea, and vomiting) for most patients, but hospice care controls most of these side effects of chemotherapy.

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