Palliative Care Referrals for Advanced Non–small-cell Lung Cancer (NSCLC): Patient and Provider Attitudes and Practices

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Abstract

Early palliative care implementation has been shown to be beneficial for patients with metastatic non–small-cell lung cancer. This study surveyed United States oncologists and patients with metastatic non–small-cell lung cancer on their practices and attitudes regarding the role of early palliative care referral. Our study highlights that few patients are referred at the time of diagnosis, likely owing to several noteworthy barriers.

Background: Early palliative care (PC) improves quality of life and prolongs survival for patients with metastatic non-small cell lung cancer (NSCLC). Despite these benefits, patient- and provider-specific barriers lead to underutilization of PC. To investigate these barriers, this 2 part study surveyed United States oncologists and patients with NSCLC. **Patients and Methods:** Oncologists in the International Association for the Study of Lung Cancer membership directory were surveyed on referral practice and attitudes regarding the role of PC for patients with NSCLC. Patients with advanced NSCLC at the Vanderbilt Ingram Cancer Center were surveyed separately regarding their understanding of PC and factors influencing them to seek referral. **Results:** Of 279 oncologists, 93 responded. Eighty-three percent believe definitive evidence exists supporting early PC; however, in practice, oncologists only refer an average of 19% of patients at diagnosis. Reasons for not referring included lack of symptoms (56%), belief that oncologists can manage PC independently (46%), not wanting to burden patients with appointments (41%), concern that referral may not be well received (38%), and long wait times (20%). Of 100 patients with NSCLC, 64% were unfamiliar with PC. Six percent had seen a PC provider. Ninety-eight percent of patients would accept referral if recommended by their oncologist. Patients desired referral for uncontrolled pain (95%), weak support system (86%), other cancer-related symptoms (85%), goals of care discussion (76%), and depression/anxiety (76%). **Conclusion:** Although most oncologists acknowledge benefits of early PC for patients with metastatic NSCLC, a minority of patients are referred. Few patients with NSCLC are familiar with PC, but most are interested in referral.

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Introduction

Lung cancer is the leading cause of cancer-related mortality in the United States, with an estimated 234,030 new cases and 154,050 deaths in 2018.[1] The median overall survival for patients with advanced stage disease treated with chemotherapy is less than 1 year, with few patients alive at 5 years. Although newer therapies have begun to improve these statistics, morbidity from therapy and disease remains high, and symptom management is an important part of patient care. As a consequence, many patients are referred to palliative care (PC) providers at some point during their disease course; however, for the majority of patients it is often within the last weeks of life. Integration of PC in the treatment of patients with cancer has resulted in more effective symptom management, improved patient understanding of their disease and prognosis, more timely transitions to hospice, decreased chemotherapy use near the end of life, improved survival, and higher levels of patient and family satisfaction.[2-10]

The timing of referral to PC is variable, and historically, there was little evidence to support when these consultations should occur.

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Many individuals have equated PC with hospice, and patients have been referred at the end-stages of disease for pain and symptom management as well as end-of-life discussions.[11,12] However, in 2010, a landmark randomized trial of 151 patients with metastatic NSCLC found that early implementation of PC at the time of diagnosis resulted in improved quality of life (QoL) and prolonged survival (median overall survival, 11.6 months vs. 8.9 months; $P = .02$).[10] These findings resulted in a shift in oncologic guidelines, with recommendations for early integration of PC for patients with metastatic disease.[13-16]

Despite the data and guideline recommendations, studies of clinical practice suggest that early PC referral may still not been widely adopted by oncologists.[17,18] Rather, physicians continue to refer patients late in their disease course, often when multiple lines of treatment have been exhausted and death is imminent. As a result, delayed referrals to PC may have less impact on a patient's QoL.[19] Several studies conducted at a limited number of medical centers have suggested that oncologists defer early referral owing to concerns about alarming their patients, a belief that they are equipped to handle patients' PC needs independently, lack of knowledge about PC services, and views that PC and chemotherapy are incompatible.[17,18,20,21] Notwithstanding the recent growth of outpatient PC clinics, increasing numbers of PC physicians, and mounting evidence regarding the benefits of early PC, it remains unclear why oncologists continue to fail to refer patients at the time of diagnosis of incurable disease.

The current research has a 2-fold objective: to examine medical oncologists' referral practices to outpatient PC providers across the United States and to investigate patients' understanding and attitudes about PC, with the goal of identifying barriers that may lead to underutilization of PC referrals. Specifically, this research focuses on patients with advanced stage NSCLC (the group of patients for whom the benefits of early referral has been most well-elucidated) and aims to determine (1) the percentage of patients with metastatic NSCLC actually referred to PC early in their disease course, (2) the factors influencing oncologists to refer patients to PC, (3) the percentage of oncologists who believe in early referral versus the percentage who actually practice this, and (4) the barriers that still exist to prevent referrals from both the patient and provider perspective.

Patients and Methods

Physician Sample and Survey Administration

Participants were identified from the 2015 International Association for the Study of Lung Cancer membership directory. Each participant was contacted via email to answer an 18-question online survey designed to be completed in under 10 minutes. Radiation oncologists, surgical oncologists, PhDs, residents, fellows, and all oncologists practicing outside of the United States were excluded. The survey was distributed on September 28, 2015, and oncologists who did not complete the questionnaire were recontacted 3 additional times via email to participate before they were considered nonresponders. Responses were anonymous. The study design and survey were institutional review board (IRB)-approved. Consent was implicit by participation. Five randomly chosen respondents were awarded $250 gift cards as incentive to complete the survey.

Patient Sample and Survey Administration

All patients with advanced stage IIIB or IV NSCLC seen at the Vanderbilt Ingram Cancer Center (VICC) in Nashville, Tennessee, with oncology clinic appointments between July and December 2017, were invited to participate. A 15-question paper survey was distributed to patients prior to their appointment. No incentives were provided to participants. The study design and survey were IRB-approved. Upon completion, patients were educated on services offered by PC and provided with an informative handout.

Physician Survey Instrument

The survey captured demographic data, including participants' gender, practice type (private vs. academic), practice location, size of practice, and years of practice. In addition, the survey addressed the following key areas: level of PC training, awareness and opinion on current evidence supporting the use of PC in patients with NSCLC, and ease of access to PC providers. To assess factors influencing oncologists to refer to PC, 13 items were listed using a 5-point Likert scale. To determine obstacles that thwart PC referral, participants were asked to identify up to 4 reasons from a list of 11. This list was comprised of commonly cited barriers in the literature and from the authors' own experiences. Finally, 2 questions asked oncologists to document the percentage of patients with metastatic NSCLC they refer at the time of first treatment initiation versus at another time when patients are actively receiving chemotherapy. The face validity of the survey was assessed independently by 4 medical oncologists and 3 PC physicians and refined accordingly. The survey is provided in Supplemental Appendix 1 (in the online version).

Patient Survey Instrument

The survey captured demographic data, including participants' age, gender, smoking status, and date of diagnosis. Patients' understanding of PC and the services provided was assessed. To determine level of understanding, participants were asked if they had heard the term "palliative care" and to provide a free-response description of what PC means to them. To determine what factors influence patients to request a referral, 9 items were listed using a 5-point Likert scale. To determine barriers to referral, participants identified potential reasons from a list of 10 commonly cited barriers in the literature. The face validity of the survey was assessed independently by the IRB, 2 medical oncologists, and 2 PC physicians and refined accordingly. The survey is provided in Supplemental Appendix 2 (in the online version).

Statistical Analysis

Statistical analysis was performed using R, version 3.2.3. The Pearson χ^2 statistic was used to test associations for each question and demographic characteristics. The proportion of responses is displayed in the summary tables for select questions. When reporting proportions, the categories "strongly (dis)agree/(dis)agree" and "very (un)likely/(un)likely" were each combined into 1 category, respectively. Percentages of referrals were reported in 4 quartiles: 0% to 25%, 26% to 50%, 51% to 75%, and 76% to 100%.

Results

Medical Oncologist Survey Results

Of 279 eligible medical oncologists, 93 (33%) completed the survey. Participants were 63% male. Ninety percent of respondents practice in an academic center, and 85% practice in a medium- (> 100,000 and < 1,000,000 people) or large- (> 1,000,000 people) size urban city. The median number of years in practice was 9. The median number of hematologists/oncologists per medical group was 35 (Table 1).

Forty-three percent of oncologists reported some form of PC training during residency or fellowship. These individuals were more likely to be in practice for less than 11 years ($P = .001$). Fifty-three percent acquired their PC knowledge by keeping abreast of PC literature. Twenty-six percent reported attending PC conferences and workshops, whereas another 26% participated in a rotation during fellowship (Table 2).

Most (88%) oncologists felt they had easy access to PC providers to whom they could refer patients, and 94% cited an affiliated PC practice within their institution. When assessing the type of PC specialist oncologists refer to, most consult physicians (94%), nurse practitioners (75%), and/or social workers (51%) (Table 2).

The majority (83%) of participants believe there is definitive evidence in the literature supporting the benefit of early PC; however, 40% feel their clinical experience only supports improvements in QoL, not prolonged survival. Approximately 24% of oncologists report being "unsure" whether their experiences with PC support improvement in QoL or prolonged survival. Opinions on this evidence did not vary by gender ($P = .33$), years in practice ($P = .81$), type of practice ($P = .39$), location of practice ($P = .60$), or history of prior PC training ($P = .95$) (Table 3).

Most (58%) oncologists "strongly agree/agree" that most, if not all, patients with metastatic NSCLC should be referred early in their disease course. Despite this, in practice, only 8% of oncologists refer more than 50% of their patients at the time of diagnosis. Approximately 81% of oncologists refer 25% or less of their patients at the time of diagnosis (mean, 19%). Participants reported a higher percentage of referrals later on in a patient's course when they are actively receiving chemotherapy; however, the majority (76%) still referred 50% or fewer of their patients. Moreover, 44% of participants state that they "rarely" refer patients to PC in the absence of symptoms (Table 3). There was no association between gender ($P = .17$), number of years in practice ($P = .95$), location of practice ($P = .30$), or history of prior PC training ($P = .81$) and early referrals to PC.

The most common factors influencing participants to refer patients to PC included inadequately managed pain (97%), weak support network (71%), no further treatment options (70%), other cancer-related symptoms (69%), depression/anxiety (68%), dwindling treatment options (66%), and lack of time to address PC needs (58%) (Table 4).

The most frequently cited reasons for not referring patients to PC included the lack of patient symptoms (56%), belief that oncologists can manage PC needs independently (46%), not wanting to burden patients with additional appointments (41%), concern that referral may not be well-received by patients (38%), and long wait times (20%). Although 38% of respondents expressed concern that PC might not be well-received by patients, 88% noted that their patients are ultimately satisfied with the PC services they receive. Few participants cited a lack of access to PC providers as a barrier to referral. Only 1 respondent cited a lack of knowledge of what PC services offer, and this individual was in a rural, private practice setting (Table 5). Other than the options listed in Table 5, several respondents noted additional barriers including a lack of follow-up from PC providers, a shortage of outpatient PC providers, and patient refusal of referral owing to misunderstanding of what PC provides.

Several barriers were more frequently noted among oncologists who refer less than 25% of their patients to PC at some point

Table 1 Baseline Characteristics

Characteristic	N	N (%)
Medical oncologists		
Gender	93	
Male		57 (63)
Female		32 (34)
NA		3 (3)
Type of practice	93	
Private		5 (5)
Academic: university practice		63 (68)
Academic: stand-alone cancer center		13 (14)
Hybrid model: university-affiliated and stand-alone cancer center		8 (9)
NA		3 (3)
Location of practice	93	
Urban: large city (>1 million people)		49 (53)
Urban: medium-size city (>100,000 and <1 million people)		30 (32)
Urban: small city (<100,000 people)		2 (2)
Suburban		5 (5)
Rural		3 (3)
NA		3 (3)
Number of hematologists/oncologists in your practice[a]	90	20.0/35.0/57.5
Number of years practicing as an attending oncologist[a]	90	5/9/20
Patients with advanced NSCLC		
Gender	100	
Male		45 (45)
Female		55 (55)
Age, y[a]		57/65/72
Smoking status		
Never-smoker		26 (26)
Former smoker		56 (56)
Current smoker		18 (18)
Time since diagnosis to survey (12/31/2017), y[a]		1.2/2.4/4.6

N is the number of non-missing values.
Abbreviations: NA = not available; NSCLC = non–small-cell lung cancer.
[a]The 3 numbers represent the lower quartile/the median/the upper quartile, respectively, for continuous variables.

Table 2 Medical Oncologists' Palliative Care Training and Access to Palliative Care

Selected Survey Questions and Responses	N (%) N = 93
Palliative care training during residency or fellowship	
Yes	40 (43)
No	53 (57)
Knowledge of palliative care (respondents may select more than one)	
Clinical rotation during residency	13 (14)
Clinical rotation during fellowship	24 (26)
Palliative care fellowship	1 (1)
Attendance at palliative care conferences and workshops during residency and/or fellowship	23 (25)
Attendance at palliative care conferences and workshops as an independent physician	24 (26)
Reading and keeping abreast of the palliative care literature	49 (53)
None of the above	16 (17)
Do you have easy access to palliative care providers to refer patients to?	
Yes	82 (88)
No	11 (12)
Does your oncology practice have an affiliated palliative care practice within the same institution?	
Yes	87 (94)
No	6 (6)
Types of palliative care providers referred to (respondents may select more than one)	
Physicians	87 (94)
Nurse practitioners	69 (74)
Physician assistants	19 (20)
Social workers	48 (52)
Case managers	22 (24)
Nurses	17 (18)
Other	6 (6)
Chaplains	1 (1)
Pharmacists	1 (1)
Psychologists/psycho-oncologists	2 (2)

Table 3 Attitudes and Practices Regarding Palliative Care Referral Among Medical Oncologists

Selected Survey Questions and Responses	N	N (%)
Is there sufficient data in the literature to support the benefit of early palliative care?	93	
There is definitive evidence		77 (83)
There is mixed evidence		11 (12)
There is marginal evidence		5 (5)
There is no evidence of benefit		0 (0)
In the 2010 NEJM article by Temel et al, patients with metastatic NSCLC had improved quality of life and prolonged survival with early palliative care. In your experience, have you observed this to be true?	93	
Yes, for quality of life; No, for prolonged survival		37 (40)
No, for quality of life; Yes, for prolonged survival		1 (1)
Yes, for both quality of life and prolonged survival		30 (32)
No, for both quality of life and prolonged survival		3 (3)
Unsure based on my experience		22 (24)
I believe that most, if not all, of my patients with metastatic NSCLC should be referred to palliative care early in their disease course.	90	
Agree		52 (58)
Neutral		20 (22)
Disagree		18 (19)
How often do you refer your patients with metastatic NSCLC to palliative care in the absence of symptoms?	89	
Always		5 (6)
Sometimes		24 (27)
Rarely		39 (44)
Never		12 (14)
Only when the patient asks		9 (10)
What percentage of your metastatic NSCLC patients do you refer to palliative care when they are actively receiving chemotherapy?	90	
0%-25%		39 (43)
26%-50%		29 (32)
51%-75%		9 (10)
76%-100%		13 (14)
What percentage of your metastatic NSCLC patients do you refer to palliative care by the time of first treatment initiation?	90	
0%-25%		73 (81)
26%-50%		9 (10)
51%-75%		4 (4)
76%-100%		4 (4)

Abbreviations: N = number of non-missing values; NEJM = New England Journal of Medicine; NSCLC = non–small-cell lung cancer.

during the course of their treatment. These include the belief that oncologists can address palliative needs independently ($P = .04$), that referral may constitute a burden to the patient ($P = .03$), and that PC needs are easier managed by the oncologist ($P = .008$). There were no significant associations when stratifying responses by the percentage of early referrals only.

Survey Results for Patients With NSCLC

Of the 100 patients approached at VICC, all completed the survey. There were 45 male and 55 female participants. The median age was 65 years (Table 1). The majority (64%) of respondents had never heard of PC prior to administration of the survey. In fact, selected responses to the prompt "Please describe your understanding of palliative care and the services it provides" included "no clue," "…maybe immunotherapy," "sounds like tongue taste buds," "heart care," "pain management," "comfy while you die, no treatment for a cure, pain relief," "for oldest and disable patient," "care for patient dying from terminal illness," "palliative care directs care with other members of the team to support the patient and body with pts with terminal illness," and "just like hospice." Only 6% of patients had been evaluated by a PC provider (Table 6). Ninety-eight percent of patients reported they would like a referral to PC if recommended by their medical oncologist. Other reasons for wanting a referral included

Table 4 Influential Factors Leading to Palliative Care Referrals

	Unlikely, N %	Neutral, N (%)	Likely, N (%)
Factors influencing medical oncologists to refer to palliative care	N = 90	N = 90	N = 90
Survey question: Please rate how the following factors influence you to refer a patient with metastatic NSCLC to palliative care.			
1) The first signs of pain or discomfort in my patient	57 (63)	16 (18)	17 (19)
2) Pain I cannot manage well myself	2 (2)	1 (1)	87 (97)
3) Lack of time to devote to palliative care treatment in my practice	21 (23)	17 (19)	52 (58)
4) At the time of initial diagnosis of metastatic disease	52 (58)	19 (21)	19 (21)
5) Dwindling treatment options	9 (10)	22 (24)	59 (66)
6) No further treatment options	8 (9)	19 (21)	63 (70)
7) Older age of patient	17 (19)	44 (49)	29 (33)
8) Patient with a weak support network	7 (8)	19 (21)	64 (71)
9) Patient with depression or anxiety	8 (9)	21 (23)	61 (68)
10) Patient with other cancer-related symptoms (ie, dyspnea, constipation, etc)	11 (12)	17 (19)	62 (69)
11) Patient requests referral	1 (1)	1 (1)	88 (98)
12) Ease of referral	2 (2)	22 (24)	66 (73)
13) Need for goals of care discussion	35 (39)	25 (28)	30 (33)
Factors influencing patients to request referral to palliative care	N = 100	N = 100	N = 100
Survey question: Please rate how the following factors would influence you to request for a palliative care referral.			
1) If I had uncontrolled pain	1 (1)	4 (4)	95 (95)
2) If I had advanced stage (metastatic) disease when I was first diagnosed	10 (10)	15 (15)	75 (75)
3) If there were LIMITED treatment options for my illness	8 (8)	14 (14)	78 (78)
4) If there were NO further treatment options for my illness	4 (4)	20 (20)	76 (76)
5) If I wanted to discuss the overall goals of my care	5 (5)	17 (17)	78 (78)
6) If I was recommended by my oncologist to meet with palliative care	0 (0)	2 (2)	98 (98)
7) If I had a weak support system	4 (4)	10 (10)	86 (86)
8) If I was depressed or anxious about my diagnosis	7 (7)	17 (17)	76 (76)
9) If I had other cancer-related symptoms (like shortness of breath, nausea, vomiting, weakness, constipation, etc.)	4 (4)	11 (11)	85 (85)

Abbreviation: NSCLC = non–small-cell lung cancer.

uncontrolled pain (95%), weak support system (86%), other cancer-related symptoms (eg, dyspnea [85%]), discussion of goals of care (76%), limited therapeutic options (76%), and depression or anxiety (76%) (Table 4). Reasons for not wanting a referral included a lack of understanding of PC services (68%), no prior discussion of PC with their medical oncologist (39%), or the belief that he/she would not be in favor of the referral (19%), the belief that choosing PC services necessitates discontinuation of cancer-directed therapy (29%), financial concerns (24%), difficulty attending multiple medical appointments (22%), long wait times (21%), and the lack of PC providers in their local communities (17%) (Table 5).

Discussion

Our results indicate that although most oncologists acknowledge the benefit of early PC for patients with metastatic NSCLC, a minority of patients are actually referred. Patients are not being referred proactively, but rather in response to diminishing treatment options, uncontrolled pain, cancer-related symptoms, and psychosocial issues. This trend continues to hold true, despite the landmark trial several years earlier with strong evidence supporting the benefit of early referral.[10]

Although oncologists recognize the benefit of early PC, a large number of oncologists believe that in practice this evidence only supports improved QoL, not prolonged survival. Only 32% of respondents in our study observed improvement in both QoL and survival, as was demonstrated in the Temel trial. Perhaps this discrepancy exists because we have yet to prove exactly why patients may live longer with early PC. It has been speculated that the correlation between early PC and prolonged survival may be related to improved QoL, lower rates of depression, and better management of symptoms leading to stabilization of a patient's condition.[10,22] Other analyses have shown lower rates of chemotherapy administration within the last 60 days of life for patients receiving early PC, which may translate into longer life expectancy owing to less treatment-related morbidity and mortality.[6] Despite these correlations though, the link between early PC and survival is not clearly definitive. In a recent Cochrane meta-analysis of early PC for patients with advanced cancer, there was no effect on survival and the effect on QoL was modest.[23] Thus, although the Temel trial demonstrated significant improvements in QoL and survival, this additional data may temper oncologists' enthusiasm for PC referral.

Table 5 Barriers to Palliative Care Referral

	N (%)
Medical oncologists	N = 90
Survey question: What are the reasons you might NOT refer a patient with metastatic NSCLC to palliative care? (You may select more than one, but please choose no more than four.)	
1) Limited professional relationship with palliative care colleagues	7 (8)
2) Referral might not be well received by the patient/might send the wrong message	34 (38)
3) Patient is not complaining of symptoms that are amenable to palliative care treatment	55 (56)
4) Belief that as an oncologist I can take care of palliative care needs myself	41 (46)
5) Don't want to burden patient with additional medical appointments	37 (41)
6) Long wait time for palliative care services	18 (20)
7) Lack of knowledge of what palliative care offers	1 (1)
8) Fear that palliative care will discourage my patient from cancer treatment	1 (1)
9) No palliative care providers located within close proximity to my practice	4 (4)
10) Patient's insurance does not cover palliative care services	10 (11)
11) It is easier for me to manage palliative care needs myself rather than refer and integrate the information back into the treatment plan	26 (29)
12) Other	10 (11)
Patients with advanced NSCLC	N = 100
Survey question: What are some reasons that you might NOT want a referral to palliative care? (You may select more than one.)	
1) It's too hard to attend multiple medical appointments	22 (22)
2) There is a long wait time for palliative care services	21 (21)
3) I'm not sure what palliative care has to offer me	68 (68)
4) Choosing palliative care services means that I can't have further cancer treatments	29 (29)
5) No palliative care providers are located near me	17 (17)
6) My insurance does not cover palliative care services.	24 (24)
7) My oncologist never discussed palliative care with me	39 (39)
8) My oncologist was not in favor of palliative care services	19 (19)
9) I was not in favor of palliative care services	9 (9)
10) Other	6 (6)

Abbreviation: NSCLC = Non–small-cell lung cancer.

Accounting for the incongruity in oncologists' beliefs and practices are many noteworthy barriers to early PC referral. In our survey, one of the most common reasons for not referring was the absence of symptoms that would seemingly be amenable to PC intervention. However, as prior studies have demonstrated, this may be the optimal time for a PC referral in this cohort of patients with metastatic disease. Despite a lack of current symptoms, metastatic NSCLC is incurable, and many of these patients will later go on to develop symptoms from their disease or therapy, including a decline in their QoL and/or difficult decision-making at the end of life. Establishing a relationship early with PC is an important complementary service to regular oncologic care and gives patients the advantage of easy access later in the disease course when the need for more palliative interventions often significantly increases.[2,10,24] Nevertheless, the most appropriate timing of referral remains to be determined and is an active area of study. A clinical trial is currently recruiting patients with advanced NSCLC comparing monthly scheduled PC visits ("early, integrated approach") to PC at the time of a change in clinical status or treatment ("stepped approach") (NCT03337399).

Although most oncologists reported easy access to PC providers, perhaps their reluctance to refer in the absence of symptoms is tied to the overall shortage of PC physicians and resultant long wait times (another commonly cited barrier). With only 6157 board-certified hospice and palliative medicine physicians in 2016 as reported by the American Medical Association (about one-half of whom work less than full time) and an increasing number of patients with cancer and longer life expectancies, there is growing demand for PC services that outpatient clinics are likely unable to meet.[25] Contributing to this problem is the uneven distribution of hospice and PC physicians across the United States, with these providers more likely to practice in and around academic centers and concentrated along the coastal regions of the United States rather than in central, and typically more rural, areas.[25] Even if PC services are available within a medical center, there is often limited availability, sometimes requiring patients to schedule additional appointments that may not be coordinated with their medical oncologist. The burden of multiple appointments coupled with an additional co-pay is a deterrent for patients when deciding whether to meet with a PC provider. Thus, it may be that many oncologists are compelled, or in some instances forced, to manage patients' PC needs themselves, only referring to PC specialists where available or when complex issues arise.

Table 6 Understanding of Palliative Care in Patients With NSCLC

Selected Survey Questions and Responses	N (%)
Have you heard of palliative care?	N = 100
Yes	36 (36)
No	64 (64)
Were you referred to palliative care?	N = 100
Yes	6 (6)
No	94 (94)
Who referred you to palliative care?	N = 6
I was referred by my oncologist	1 (17)
I was referred by another one of my doctors	2 (33)
I was referred by a doctor other than my regular doctors	3 (50)
I referred myself	0 (0)
Other	0 (0)
How long after first learning about your diagnosis of metastatic (widespread) lung cancer were you referred to palliative care?	N = 6
Immediately when I was diagnosed	2 (33)
Days	1 (17)
Weeks	1 (17)
Months	1 (17)
One year or longer	1 (17)
Which types of palliative care providers have you seen? (You may select more than one)	N = 6
Doctors	4 (67)
Nurse practitioner (NP)	1 (17)
Physician assistant (PA)	0 (0)
Social worker	0 (0)
Case manager	1 (17)
Nurse	1 (17)
Other	0 (0)
How satisfied have you been with the services that palliative care has to offer?	N = 6
Very satisfied	2 (33)
Satisfied	1 (17)
Neutral	1 (17)
Unsatisfied	0 (0)
Very unsatisfied	1 (17)
Unsure	1 (17)

According to our survey, only 43% of oncologists had some form of PC training in residency or fellowship (most of which was in the form of self-education), whereas many of them delay early PC referral as they believe they can manage these needs themselves. This belief was one of the few barriers demonstrating a statistically significant association with lower rates of referral. This finding is in line with a prior qualitative study, where interviews of medical oncologists revealed a prevailing belief that PC falls within the domain of the oncologist.[21] Although some oncologists may have the skills and time to do so, research has highlighted that this is often not the case. In a study of outpatient PC and medical oncology appointments, it was found that although both sessions address patients' symptoms, PC visits more commonly and comprehensively focus on important psychosocial issues.[26] With oncologists focused on increasingly complex treatment plans, there is less time to adequately address all of a patient's PC needs.

Another frequently cited barrier was the notion that it may be easier for oncologists to address PC needs themselves, rather than refer and have to integrate that information back into their own treatment plan. This barrier also showed a statistically significant association with the lowest rates of referrals. Although there are multiple reasons why oncologists may relate to this, it suggests the need for a more collaborative model of care between these 2 specialties.

Apprehension that PC might discourage patients from further chemotherapy was not shared by the oncologists in our survey; however, they did cite concerns that early referral might "send the wrong message" to patients. This was in spite of also noting that most patients are ultimately satisfied with the PC services they receive. This reluctance to avoid alarming patients has been cited in prior research as well.[16] Interestingly, when the name 'palliative care' is switched to 'supportive care,' early referral rates increase, as oncologists believe it will be better received by their patients.[27] However, little evidence exists that PC referral is distressing to patients.[28-30] Patients who understand and appreciate the benefits of early PC as well as the difference between hospice and PC are more likely to request and participate in early referral. In fact, our survey demonstrates that the majority of patients are open to PC referral, especially if their medical oncologist recommended it and care was easily accessible.

There are several limitations of this study. First, the oncologist-specific survey was primarily answered by physicians in large academic medical centers, which is partially a product of using the International Association for the Study of Lung Cancer directory as our sample. Thus, our results may not be generalizable to smaller practices and community settings. However, it is anticipated that barriers to referral would be even more pronounced in these areas where PC is often less accessible. Second, the study design relied on oncologists to self-report their percentage of referrals in open-ended questions rather than directly observing behavior. Third, a higher response rate among oncologists may have bolstered the power of our study and ultimately our findings. However, our physician response rate of 33% is not far from rates cited in similar studies using survey methodology.[17,20,21] Regarding the patient cohort of our study, these individuals received oncologic care from only 2 practicing medical oncologists at VICC; thus, this is a limited sample and may present bias. As with most surveys, there is potential for response bias, and it was not possible to compare characteristics of respondents and non-respondents. Furthermore, we did not collect data regarding patients' socioeconomic and/or educational status, both of which have potential to influence their perspective on the utility of PC referral. Lastly, the timing of our PC survey may be another limitation, as all patient participants were surveyed exclusively in an outpatient setting during scheduled follow-up visits with their medical oncologist. We felt that limiting our study population to patients with an established medical oncologist was ideal; however, it is unclear how the perspectives of this cohort might compare with patients new to an oncology practice or in an inpatient setting.

Our study is unique in that it focuses on medical oncologists across the United States in a variety of settings. Prior research has involved providers from only a few regional hospitals or at institutions outside the United States, including sites with already established PC clinics,

or relied only on interview methodology.[17,18,21] Further, our study focuses on medical oncologists rather than other healthcare providers, as this group is most frequently making decisions regarding referral to PC. Our survey was also conducted several years after many of the prior studies, allowing for an assessment of progress in the field. Additionally, we pose a novel question of whether oncologists believe there is sufficient data in the literature to support the benefit of early PC. Finally, we incorporate an assessment of important referral barriers from a patient perspective.

More efforts are needed to promote early PC referral. As most oncologists in our survey already acknowledge the benefit of early referral, educational efforts directed at this group may not result in dramatic improvements. Rather, system-based issues should be addressed to allow referrals to more readily occur. We need expansion of PC training programs to increase the number of PC physicians and reduce appointment wait times. Medical centers should further strive to create multi-disciplinary, integrated teams of oncologists and PC providers as a way to foster collaboration between the specialties and earlier consultation.

Conclusion

Although medical oncologists acknowledge the evidence-based benefit of early PC consultation for patients with metastatic NSCLC, a minority of patients are referred. Our survey highlights noteworthy barriers to explain this discrepancy. Many patients with advanced NSCLC remain unfamiliar with PC services, but would welcome referral, especially if recommended by their medical oncologist.

Clinical Practice Points

- It has been shown that early implementation of PC improves QoL and prolongs survival for patients with advanced stage NSCLC. Unfortunately, many of these patients are not referred to PC providers until the last weeks of life and are thus unable to obtain the full extent of these benefits.
- This study uniquely identifies barriers to early PC referral from both patient and provider perspectives. Although many medical oncologists agree that definitive evidence exists supporting early PC, providers often defer referral given patients' lack of symptoms, belief that oncologists can manage PC independently, and not wanting to burden patients with appointments. Many patients with NSCLC would welcome a referral to PC for additional symptom management, especially if their medical oncologist recommended it and care was easily accessible.
- These results highlight the need to educate patients with cancer on PC and to increase efforts to ensure greater access to PC services within cancer communities.

Disclosure

Leora Horn reports paid consulting for Abbvie, BMS, Genentech, Lilly, and Merck; unpaid consulting for Xcovery and Bayer; and travel from Betta and Xcovery. The remaining authors have stated that they have no conflicts of interest.

Supplemental Data

Supplemental appendices accompanying this article can be found in the online version at https://doi.org/10.1016/j.cllc.2019.02.002.

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