



Palliative care use and utilization determinants among patients treated for advanced stage lung cancer care in the community and academic medical setting

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Abstract

Purpose Despite clinical guidelines, palliative care is underutilized during advanced stage lung cancer treatment. To inform interventions to increase its use, patient-level barriers and facilitators (i.e., determinants) need to be characterized, especially among patients living in rural areas or those receiving treatment outside academic medical centers.

Methods Between 2020 and 2021, advanced stage lung cancer patients ($n = 77$; 62% rural; 58% receiving care in the community) completed a one-time survey assessing palliative care use and its determinants. Univariate and bivariate analyses described palliative care use and determinants and compared scores by patient demographic (e.g., rural vs. urban) and treatment setting (e.g., community vs. academic medical center) factors.

Results Roughly half said they had never met with a palliative care doctor (49.4%) or nurse (58.4%) as part of cancer care. Only 18% said they knew what palliative care was and could explain it; 17% thought it was the same as hospice. After palliative care was distinguished from hospice, the most frequently cited reasons patients stated they would not seek palliative care were uncertainty about what it would offer (65%), concerns about insurance coverage (63%), difficulty attending multiple appointments (60%), and lack of discussion with an oncologist (59%). The most common reasons patients stated they would seek palliative care were a desire to control pain (62%), oncologist recommendation (58%), and coping support for family and friends (55%).

Conclusion Interventions should address knowledge and misconceptions, assess care needs, and facilitate communication between patients and oncologists about palliative care.

Keywords Palliative care · Advanced stage lung cancer · Barriers · Facilitators

Introduction

Lung cancer is the leading cause of cancer mortality in the United States and the second most common cancer among men and women [1]. Psychosocial and physical concerns are prevalent among lung cancer patients [2, 3]. Rigorous randomized controlled trials have shown providing patients with outpatient specialty palliative care during lung cancer

treatment addresses common psychosocial and physical concerns, improves quality of life and facilitates end-of-life care [4–6]. As such, practice guidelines recommend palliative care be delivered concurrently with cancer treatment for advanced stage lung cancer patients [7].

Unfortunately, less than 30% of patients with advanced stage lung cancer receive palliative care within a year of diagnosis [8]. Patients who reside in rural areas or receive care in the community (vs. academic medical center) may be at increased risk for underutilization [9], presumably because of palliative care provider scarcity. However, research conducted in academic medical centers where palliative care is readily available, yet underutilized, suggest palliative care utilization is determined by intrapersonal (e.g., knowledge, attitudes, beliefs) and interpersonal factors (e.g., patient-provider

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communication)[10]. These factors have not been well-described among advanced stage lung cancer patients, especially among those residing in rural areas or receiving care in the community. This is a major limitation, as lung cancer is more common in rural areas [11], most patients are treated in the community [12, 13], and rural and community-treated patients may have less exposure to palliative care in their social networks and face more attitudinal and logistical barriers to seeking supportive care. [14]

The goal of the current study was to identify palliative care use and determinants (i.e., knowledge, misperceptions, and reasons for or against using palliative care) among patients receiving treatment for advanced stage lung cancer in an academic medical center or community practice. A secondary goal was to examine palliative care use and determinants based on patient residence (rural vs. urban), treatment setting (academic vs. community), age, and sex. We chose these factors based on the PROGRESS-Plus Framework of social determinants of health and prior literature [14–16]. We hypothesized patients who resided in rural areas, received treatment in the community, were older, and male would have less knowledge of palliative care and be more likely to report palliative care misperceptions.

Methods and materials

Study design

Data were collected from a National Cancer Institute-designated Cancer Center and three community oncology sites in Kentucky, US, as part of a multilevel assessment (i.e., patients, providers, and administrators) of palliative care determinants. Community sites were located 1–2 h from the academic medical center. All community sites were accredited by the American College of Surgeons Commission on Cancer and assessed no more than 500 new cancer cases a year. Because of Commission on Cancer accreditation, all had been required to provide palliative care on site or by referral since 2012. At the time of this study, two sites offered outpatient palliative care; the NCI-designated academic medical center and remaining community site only offered inpatient palliative care. Recruitment occurred between July 2020 and July 2021. The recruitment period was prolonged from an intended 6-month target due to COVID-related research support staffing shortages at community sites. Patients were identified by screening oncology schedules using the electronic medical record system. Site coordinators approached eligible patients in clinic or remotely and reviewed a study information sheet. All patients provided informed consent. The University of Kentucky Medical Institutional Review Board approved this study (#55171). Participants received \$30.

Participants

Patients were eligible if they were age 18 years or older, spoke English, and were undergoing treatment for advanced stage lung cancer (stage IIIb, IIIc, IV non-small cell lung cancer; extensive stage small cell lung cancer).

Measures

Sociodemographic factors

Patients self-reported sex, age, race, ethnicity, education, employment status, insurance, travel time to cancer care, current and past cancer treatments (e.g., chemotherapy, radiation, immunotherapy) and history of other cancers. Rural residence was determined by the Federal Office of Rural Health Policy's eligible ZIP codes; any ZIP code with more than 50% of the population residing in a non-metro county or rural census tract was considered rural. Current smoking status (i.e., past month) was assessed with the 4-item base of the Cancer Patient Tobacco Use Questionnaire[17].

Palliative care use

Patients self-reported whether they had met with a palliative care doctor and palliative care nurse as part of their cancer care. Response options included “Never,” “Occasionally,” “Often,” and “Don't know.” For bivariate analyses, responses were collapsed to “Never,” “Occasionally/Often,” and “Don't know.”

Palliative care knowledge

Items from the Health Information National Trends Survey[18] assessed perceived palliative care knowledge (e.g., “I know what palliative care is and could explain it to someone else,”), functions (4 items; e.g., “To me, the goal of palliative care is to manage pain and other physical symptoms), and perceptions (5 items). Three perception items were considered misconceptions (e.g., “If you accept palliative care, you must stop other treatments”). Participants responded to these items via a Likert-type scale, where 1 = “strongly disagree” and 4 = “strongly agree.” Participants could also respond “don't know.” For analysis, responses were collapsed to “agree/strongly agree,” “strongly disagree/disagree,” or “don't know.” Each item was examined separately. Patients were considered to have endorsed a misconception if they agreed or strongly agreed.

Non-hospice palliative care (NHPC) attitudes

After patients answered questions about palliative care use and knowledge, they were provided with the following

description of “non-hospice palliative care” as part of instructions for completing the Palliative Care Attitudes Scale [19]: *This section asks you some questions about your beliefs about aspects of health and healthcare, particularly something called “Non-hospice Palliative Care.” Non-hospice palliative care involves discussing ways to address physical symptoms, side effects, and emotional concerns, but it can also help patients and their families with difficult decisions and end-of-life issues during cancer treatment. Non-hospice palliative care can be delivered by a cancer doctor and/or with a team of providers, such as a doctor, a nurse, a psychologist, a nutritionist, and/or a social worker.* The term “non-hospice palliative care,” a term standardly used to help differentiate end-of-life palliative care from palliative care provided alongside life-prolonging treatments [20, 21], was used intentionally to help ensure patients answered subsequent questions without mistakenly conflating palliative care with hospice. The Palliative Care Attitudes Scale (PCAS) contains nine items (e.g., “Do you think the visits would help with feelings of sadness and depression?”) related to palliative care. Items were modified to substitute “non-hospice palliative care” for “palliative care,” were responded to on 5-point Likert-type scales with response options that varied by subscale, and summed to yield a total score, with higher scores indicating more positive attitudes. Internal consistency in this sample was good (Cronbach’s $\alpha = 0.84$).

Barriers and facilitators to non-hospice palliative care

This measure was adapted from another study [10] (see Supplemental Material) and administered after the PCAS. Patients were instructed to rate how factors would influence them to request a non-hospice palliative care visit (i.e., facilitator) or be a reason they would not want to have a non-hospice palliative care visit (i.e., barrier). Instructions further stated, “Starting non-hospice palliative care does not mean you have to stop cancer treatment.” Barriers (e.g., “I am afraid my insurance would not cover non-hospice palliative care”) and facilitators (e.g., “If my oncologist recommended I meet with non-hospice palliative care”) were responded to on a Likert-type scale (facilitators; 1 = very unlikely to 5 = very likely; barriers 1 = not at all a barrier to 5 = very much a barrier). Due to small cell sizes, response were collapsed for analysis (“not at all”/“slight” = not a barrier; “somewhat”/“moderate”/“very much” = barrier; “very unlikely”/“unlikely”/“neutral” = not facilitator; “likely”/“very likely” = facilitator). We also examined the proportion reporting each as a major barrier (“very much a barrier”) or strong facilitator (“very likely facilitator”). In analyses examining whether barriers or facilitators differed by clinical or sociodemographic characteristics, we used three barrier (“not at all”/“slight” = not a barrier; “somewhat/moderate” = moderate barrier; “very much” = major

barrier) and facilitator categories (“very unlikely”/“unlikely”/“neutral” = not facilitator; “likely” = facilitator; “very likely” = strong facilitator).

Statistical analyses

Univariate means and standard deviations and percentages were used to describe palliative care outcomes. Bivariate tests compared patients within two designations of rural residence (i.e., rural vs. urban) and cancer care facility (i.e., academic medical vs. community cancer center) for these variables. Follow-up analyses compared outcomes by outpatient palliative care access at sites (outpatient services available/not available). We used chi-square or Fisher’s exact tests for categorical variables and two-sample t-tests or one-way ANOVA for continuous variables. All analyses were conducted in SPSS. A two-tailed alpha of 0.05 was used.

Results

Study population

Screening identified 137 eligible patients, of whom 110 were contacted and approached; 77 (70%) completed the survey; 24 (22%) refused; nine (8%) were lost to follow-up. Reasons for refusal included: “Just do not want to” ($n = 6$); “Too much going on” ($n = 6$); “Topic not of interest” ($n = 5$); “Not feeling well enough physically” ($n = 2$); “Not feeling well enough mentally” ($n = 2$); and “Do not have time” ($n = 2$). Refusal reason was missing for one patient. Patients who refused to participate were not significantly different from those who enrolled with respect to age, sex or education.

See Table 1 for demographic and clinical characteristics. Age, education, sex, and health literacy were not significantly different based on rural residence or cancer facility. Rural patients comprised 53.3% of the sample from a community site vs. 75.0% of the sample from the academic medical center ($p = 0.06$). 62.5% of patients treated in the academic medical center traveled an hour or more for cancer care vs. 8.9% of those treated in the community ($p < 0.001$).

Palliative care use

Roughly half (49.4%) reported they had never met with a palliative care doctor as part of their cancer care; 20.8% reported occasionally meeting with one; 11.7% reported often meeting with one; 15.6% did not know if they had met with a palliative care doctor. Over half (58.4%) reported they had never met with a palliative care nurse as part of their cancer care; 11.7% reported occasionally meeting with one; 10.4% reported often meeting with one; and 15.6% did not know.

Table 1 Sociodemographic and clinical characteristics of patients ($N=77$)

Sociodemographics	n (%) / Mean (SD)
Age – Mean (SD)	64.69 ± 10.31; range 39–88
Race – n (%)	
White	74 (96.1%)
Black	2 (2.6%)
Missing	1 (1.3%)
Female – n (%)	38 (49.4%)
Currently Married or Partnered –n (%)	53 (68.8%)
Rural^a – n (%)	48 (62.3%)
Education –n (%)	
HS diploma	29 (37.7%)
Some HS or less	16 (20.8%)
College graduate or more	12 (15.6%)
Some college	11 (14.3%)
Post-high school training	8 (10.4%)
Missing	1 (1.3%)
Current Employment Status	
Retired	32 (41.6%)
Disabled	24 (31.2%)
Unemployed	8 (10.4%)
Working full time	6 (7.8%)
Homemaker	3 (3.9%)
Working part time	3 (3.9%)
Missing	1 (1.3%)
Another Person Accompanies Patient to Medical Appointment	61 (79.2%)
Commute to Cancer Doctor's Office	
30 min or less	29 (37.7%)
31–45 min	15 (19.5%)
46–60 min	9 (11.7%)
1 h to 1.5 h	12 (15.6%)
More than 1.5 h	12 (15.6%)
2–2.5 h	5
3–4 h	5
Missing commute time over 1.5 h	2
Health Insurance*	
Medicare	39 (50.7%)
Medicaid, Medical Assistance, or government-assistance plan	26 (33.8%)
Insurance through current/former employer or union	19 (24.7%)
Insurance purchased directly from an insurance company	5 (6.5%)
VA	3 (3.9%)
TRICARE or other military health care	2 (2.6%)
Clinical	
Receiving Cancer Treatment at Community Site	45 (58.4%)
Currently Smoking – n (%)	24 (31.2%)
Treatments Currently Being Received*	
Chemotherapy	48 (62.3%)
Immunotherapy	41 (53.3%)
Radiation	8 (10.4%)
Other	5 (6.5%)
Gamma knife®	2 (2.6%)
Other Treatments Received to Date* – n (%)	
Chemotherapy	39 (50.7%)

Table 1 (continued)

Sociodemographics	n (%) / Mean (SD)
Radiation	38 (49.4%)
Immunotherapy	17 (22.1%)
Gamma knife®	8 (10.4%)
Stereotactic body radiation therapy	1 (1.3%)
Other	3 (3.9%)
History of More Than One Cancer* – n (%)	28 (36.4%)
Previous lung	8 (10.4%)
Head and neck (thyroid, esophagus)	4 (5.2%)
Melanoma	3 (3.9%)
Breast	2 (2.6%)
Gynecologic (cervical, ovarian)	2 (2.6%)
Liver	1 (1.3%)
Colorectal	1 (1.3%)
Other	12 (15.6%)

n = sample size; *SD* = standard deviation; *HS* = high school; *VA* = Veterans Affairs

^aRural = Federal Office of Rural Health Policy’s eligible ZIP codes (ZIP code with more than 50% of the population residing in a non-metro county or rural census tract included as rural)

^bCurrently smoking = reported smoking a cigarette within the past 30 days

*Do not sum to 100%, as patients could indicate more than one option

Patients treated in the community were more likely to report having seen a palliative care doctor compared to patients treated in an academic medical center (45.5% vs. 16.2%, *p* = 0.024). Follow-up analysis suggested this difference was driven by two community sites in which 50% and 53.8% of patients reported having seen a palliative care doctor compared to 16.2% (academic medical center) and 25% (third community site; *p* = 0.129); both community sites with at least 50% reporting they had seen a palliative care doctor offered outpatient palliative care onsite. None of the other pre-specified factors were associated with palliative care use.

Palliative care knowledge, misconceptions, and functions

Only 18.2% (*n* = 14) reported they knew what palliative care was and could explain it (Table 2). Patients’ self-reported knowledge of palliative care was not significantly different by cancer treatment facility (community vs. academic medical center), residence (rural vs. urban), or availability of outpatient palliative care onsite (Table 2). 34.2% of women vs. 52.6% of men had never heard of palliative care (*p* = 0.052). Age was not significantly different across knowledge responses (*M* age for those who had never heard of palliative care = 66.7; *SD* = 10.0; *M* age for those who knew a

Table 2 Self-Reported Palliative Care Knowledge among Advanced Stage Lung Cancer Patients Overall and by Residence, Treatment Setting, and Availability of Outpatient Palliative Care

	Overall Sample (<i>N</i> = 76) ^a	Rural vs. Urban		<i>p</i>	Community vs. Academic Medical Center		<i>p</i>	Outpatient Palliative Care Available vs. Unavailable		<i>p</i>
		Rural (<i>n</i> = 47) ^a	Urban (<i>n</i> = 29) ^a		Community (<i>n</i> = 44) ^a	Academic (<i>n</i> = 32) ^a		Available (<i>n</i> = 31) ^a	Unavailable (<i>n</i> = 45) ^a	
Palliative care knowledge										
Never heard of it	33 (42.9%)	22 (46.8%)	11 (37.9%)	.78	17 (38.6%)	16 (50.0%)	.56	11 (35.5%)	22 (48.9%)	.49
Know a little bit	29 (37.7%)	17 (36.2%)	12 (41.4%)		19 (43.2%)	10 (31.3%)		13 (41.9%)	16 (35.6%)	
Know what it is and could explain it	14 (18.2%)	8 (17.0%)	6 (20.7%)		8 (18.2%)	6 (18.8%)		7 (22.6%)	7 (15.6%)	

Note. *NHPC* = non-hospice palliative care. Statistical significance was tested with Fisher’s exact tests. ^aTotal sample size was 77 patients; responses were missing from 1 person

little = 64.3, SD = 10.6; knew what it was and could explain it = 60.4; SD = 10.0, $p = 0.158$).

When presented with misconceptions (e.g., accepting palliative care means giving up), between 30–38% said they did not know (Fig. 1a). 16.9% ($n = 13$) reported palliative care was the same as hospice and using it meant giving up. Between 26–32% did not know whether some of the functions of palliative care were accurate (e.g., helps manage pain and other physical symptoms; Fig. 1b). Most (53.3%; $n = 41$) thought it was a doctor’s responsibility to inform patients of the option of palliative care (Fig. 1b).

Non-hospice palliative care (NHPC)

Attitudes

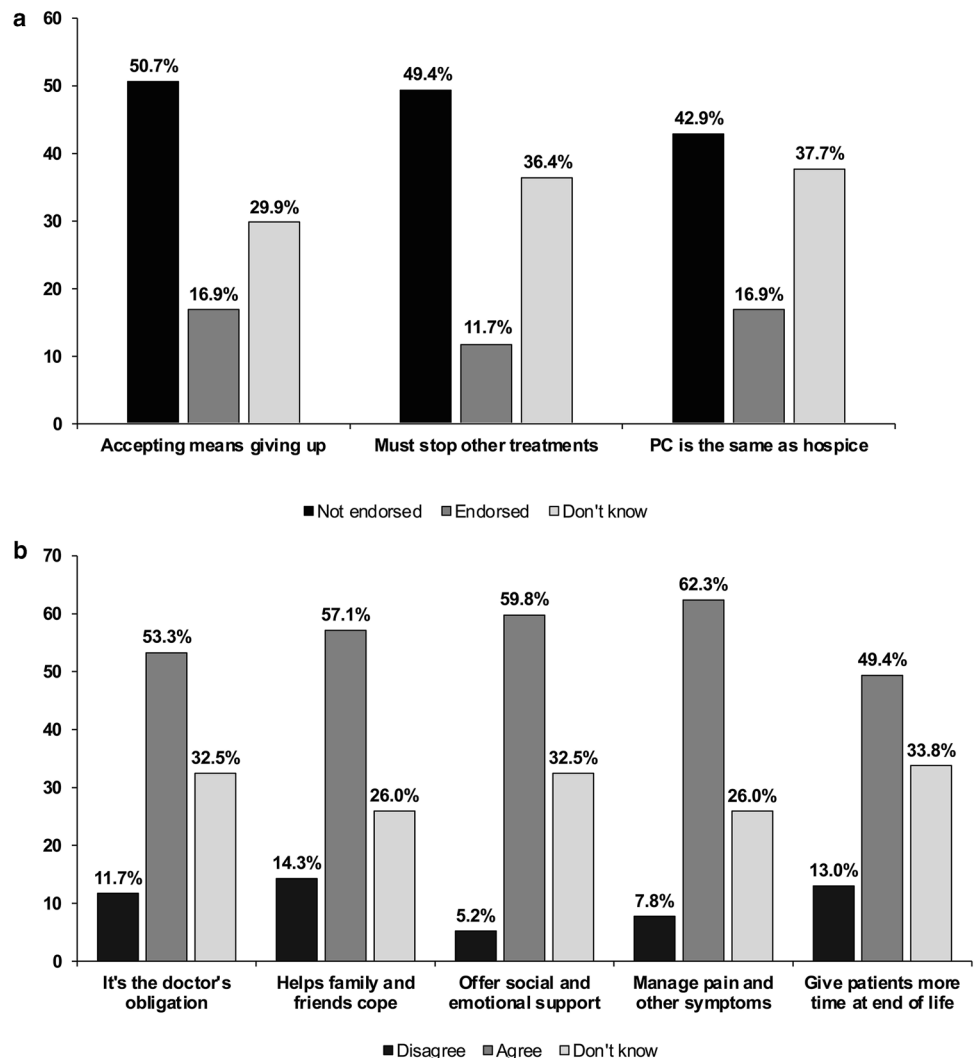
Patients reported positive attitudes towards NHPC ($M = 24.83$; $SD = 7.98$; range = 6–45). Attitudes towards NHPC were not significantly different by cancer treatment

facility ($M = 23.2$; $SD = 7.16$ among academic medical center patients vs. $M = 26.0$; $SD = 8.41$ among community cancer patients; $p = 0.14$) or whether outpatient palliative care was available onsite ($M = 23.88$; $SD = 8.25$ among patients treated where outpatient palliative care was not available vs. $M = 26.17$; $SD = 7.52$ among those where outpatient palliative care was available, $p = 0.233$). Attitudes towards NHPC were also not significantly different by residence ($M = 24.54$, $SD = 7.17$ for rural patients; $M = 25.35$, $SD = 9.38$ for urban patients, $p = 0.71$), age ($r = -0.01$, $p = 0.93$), or sex (M men = 24.5; $SD = 7.4$; M female = 25.2; $SD = 8.6$, $p = 0.73$).

Barriers to non-hospice palliative care

The most common stated barrier to seeking non-hospice palliative care was being unsure what it would offer (64.9%, $n = 50$; Fig. 2a), followed by insurance coverage concerns (62.3%, $n = 48$), oncologist not discussing it (59.7%, $n = 46$)

Fig. 1 a Proportion of patients endorsing misconceptions of palliative care ($N = 77$). Note: “PC” = Palliative care. **b** Perception of palliative care functions and doctor obligation’s to discuss it ($N = 77$). Note: “It’s the doctor’s obligation” – verbatim item was “It is the doctor’s obligation to inform all patients with cancer about the option of palliative care”. Percentages do not sum to 100% as responses were missing from 2-3 people



and difficulty attending multiple appointments (59.7%, $n=46$). Of stated barriers, the most common “major barrier” was concern insurance would not cover it (28.6%; $n=22$; Fig. 2a), followed by an oncologist not discussing it with them (23.4%; $n=18$). Barriers were not significantly different based on pre-specified patient demographic factors, treatment facility, or availability of outpatient palliative care onsite, though several differences in magnitude were in the expected direction (Supplemental Table 1).

Facilitators to non-hospice palliative care

The most common reasons patients reported they would seek non-hospice palliative care were to manage uncontrolled pain (62.4%; $n=48$; Fig. 2b), if an oncologist recommended it (58.5%; $n=45$), or to help family and friends cope (54.6%; $n=42$). These facilitators were also the most frequently reported “very likely” facilitators (Fig. 2b).

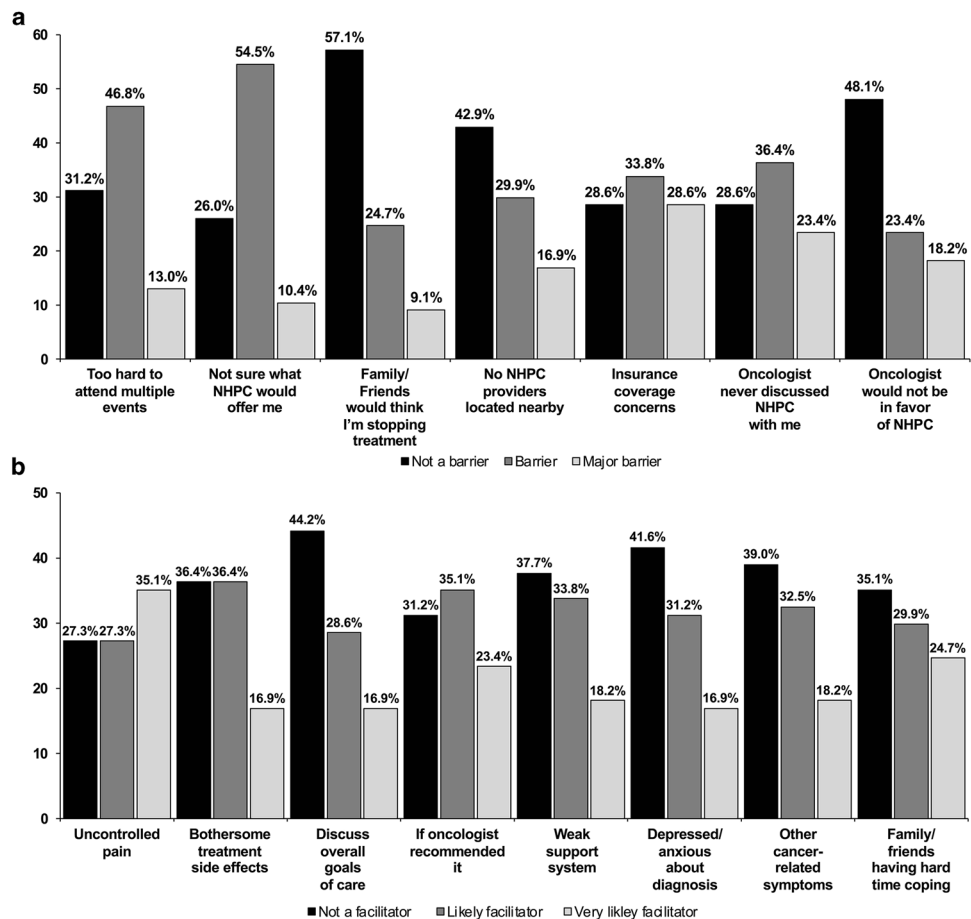
Facilitators were not significantly different based on cancer treatment facility, patient residence, or availability of outpatient palliative care onsite (Supplemental Table 2). Women were more likely to report that a weak support system would be a reason for them to seek non-hospice palliative (32.4% of women vs. 8.6% of men, $p=0.047$). Older

patients were more likely to report an oncologist recommending non-hospice palliative care would be a reason for them to seek it (Mage “not facilitator” = 59.5, SD = 10.6, “likely facilitator” = 65.3, SD = 10.3, “very likely facilitator” = 67.5, SD = 7.3, $p=0.02$).

Discussion

This is among the first studies to describe palliative care use and determinants among patients with advanced stage lung cancer and the first to examine patient perspectives from both academic and community-based treatment facilities [10]. Overall, we found that although many patients reported having seen a palliative care provider during cancer care, palliative care knowledge was low and many mistakenly conflated it with hospice. The barriers and facilitators identified to using palliative care once we differentiated it from hospice suggested that (beyond addressing misconceptions) patient-level interventions to increase palliative care use among advanced stage lung cancer patients should: educate patients about palliative care’s role in cancer treatment; discuss insurance coverage and costs of using palliative care; facilitate palliative care discussions with oncology providers;

Fig. 2 a Proportion of patients endorsing each barrier to seeking non-hospice palliative care (NHPC; $N=77$). b Proportion of patients endorsing each facilitator to utilizing non-hospice palliative care (NHPC; $N=77$). Note: Percentages do not sum to 100%, as missing responses ranged from 7-9 people



and reduce the burden of additional medical appointments associated with palliative care. In most instances, subgroup analyses did not suggest determinants differed based on patient characteristics, treatment setting, or availability of outpatient palliative care onsite, suggesting patient-level intervention strategies identified may be broadly applicable.

Encouragingly, about half of patients reported having seen a palliative care provider as part of their cancer care – a significantly higher proportion than the estimated 12–30% from electronic health record and claims data studies [8, 22]. Because two community sites sampled offered outpatient palliative care on site, it is possible this high proportion reflects use when palliative care is better integrated into routine oncology care. Indeed, patients treated at our NCI-designated cancer center which did not offer outpatient palliative care were less likely to report having seen a palliative care doctor. However, it is also possible, and perhaps more likely, that some patients may have mistakenly reported seeing a palliative care provider, as over 40% had never heard of palliative care.

Patients in this study had very low knowledge of palliative care regardless of treatment facility, outpatient palliative care availability onsite, and patient residence. Though not statistically significant, a higher proportion of men vs. women had never heard of palliative care. By virtue of being less likely to assume a role of informal caregiver [23], men may have had less exposure to palliative care. It is also possible men may have been less likely to receive information about palliative care because they are assumed to be less interested in it. Contrary to our findings, prior research has found men have less favorable attitudes towards palliative care and are less likely to receive it (though, interestingly, men seemed to benefit *more* from palliative care in the landmark trial of palliative care in lung cancer)[24, 25]. Sex differences in palliative care use and determinants should continue to be studied to inform intervention tailoring.

In addition to low stated knowledge of palliative care, we found knowledge deficits regarding palliative care's distinction from hospice and its role in cancer treatment. Between 12–20% endorsed common misconceptions about palliative care, mistakenly assuming it is the same as hospice; means giving up; or requires stopping cancer treatment. Further, between 26–32% did not know about palliative care's role in treatment (e.g., that it could help manage pain and other physical symptoms). The proportion of patients endorsing misconceptions was much lower than in other studies [26–28], presumably because we allowed “don't know” responding. About a third of the sample responded “don't know” to misconception items. Particularly for patients who conflated palliative care with solely end-of-life care, “don't know” responses could have functioned as a way to avoid experiencing uncomfortable thoughts associated with palliative care [29].

A unique strength of this study was that after assessing palliative care knowledge and misconceptions, we provided patients with a description of palliative care that we thought would address the major misconceptions patients have about it (i.e., that it is the same as hospice and using it means stopping treatment) and then asked patients to indicate reasons they would or would not use “non-hospice palliative care” [20, 21]. We did this to identify determinants beyond the most identified barriers of conflating palliative care with hospice or “giving up”[30, 31]. Patients reported they would seek non-hospice palliative care to manage a variety of concerns and care needs, including uncontrolled pain, treatment side effects, and depression and anxiety, to support friends and family's coping, and to discuss goals of care. They also stated they would seek non-hospice palliative care if their oncologist recommended it. An oncologist's recommendation seemed particularly important to older patients, which is consistent with prior research suggesting older people prefer to receive information from a provider vs. other source [22]. Patients also endorsed several reasons for not using non-hospice palliative care, including uncertainty about its benefits; lack of discussion with an oncologist; difficulty attending additional medical appointments (perhaps more so for patients at an academic medical center); and concern about insurance coverage. These results align with other findings pointing to the critical role of oncology providers' support of palliative care [32], need for remote delivery options[33], and cost discussions and assistance [34].

This study was conducted during the height of the initial wave of the COVID-19 pandemic, which likely reduced participation, though our participation rate was still relatively high (70%). Other study limitations include a cross-sectional design, limited statistical power for detecting subgroup differences, self-report of palliative care utilization, and a predominantly White, non-Hispanic sample. This reflects the demographics of the region but limits generalizability. We did not assess other barriers and facilitators that may be salient among people from other backgrounds [35]. We also asked patients to indicate hypothetical reasons they would or would not use “non-hospice palliative care,” and not reasons why they had or had not already seen a palliative care provider. However, because palliative care knowledge deficits and misconceptions are common and a major deterrent to palliative care use [36], identifying additional determinants almost requires a hypothetical framework like we used to further assess determinants in this study. Additional strengths include a high response rate; assessment of patients from both an academic and community setting; and strong rural representation.

Conclusion

Interventions to increase palliative care utilization among patients with advanced stage lung cancer need to address knowledge, misconceptions, and care delivery barriers, including lack of oncology provider discussions of palliative care during cancer treatment and cost and time concerns. Interventions should also assess patients' care needs and inform patients of palliative care's role in addressing those needs with their oncologist.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00520-023-07649-y>.

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Availability of data and materials The dataset generated and analyzed in this study is available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Institutional Review Board at the University of Kentucky (#55171). All participants provided informed consent. Written documentation of informed consent was waived for this study.

Consent for Publication Not applicable.

Competing interests The authors have no relevant financial or non-financial interests to disclose.

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