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Clinician Perspectives on Delivering Primary and Specialty Palliative Care in Community Oncology Practices

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Abstract

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Purpose: Clinical guidelines recommend early palliative care for patients with advanced lung cancer. In rural and underserved community oncology practices with limited resources, both primary palliative care from an oncologist and specialty palliative care are needed to address patients' palliative care needs. The aim of this study is to describe community oncology clinicians' primary palliative care practices and perspectives on integrating specialty palliative care into routine advanced lung cancer treatment in rural and underserved communities.

Methods: Participants were clinicians recruited from fifteen predominantly rural community oncology practices in Kentucky. Participants completed a one-time survey regarding their primary palliative care practices and knowledge, barriers, and facilitators to integrating specialty palliative care into advanced stage lung cancer treatment.

Results: 47 clinicians (30% oncologists) participated. The majority (72.3%) of clinicians worked in a rural county. Over 70% reported routinely asking patients about symptom and physical function concerns, whereas less than half reported routinely asking about key prognostic concerns. Roughly 30% held at least one palliative care misconception (e.g., palliative care is for only those who are stopping cancer treatment). Clinician-reported barriers to specialty palliative care referrals included: fear a referral would send the wrong message to patients (77%) and concern about burdening patients with appointments (53%). Notably, the most common clinician-reported facilitator was a patient asking for a referral (93.6%).

Conclusion: Educational programs and outreach efforts are needed to inform community oncology clinicians about palliative care, empower patients to request referrals, and facilitate patients' palliative care needs assessment, documentation, and standardized referral templates.

Keywords

Advanced stage lung cancer; Palliative care; Clinicians; Community Practice

Introduction

With evidence demonstrating benefits for quality of life,[1] professional oncology societies recommend early integrated palliative care for patients undergoing treatment for advanced lung cancer for 20 years.[2,3] However, implementing this recommendation has been difficult,[3] with a combination of multilevel factors, including patient and provider misconceptions about palliative care,[4–7] specialty palliative care provider scarcity in rural areas,[8, 9] and perhaps even therapeutic advances in the treatment of advanced lung cancer.[2,7,2] Given these factors, experts recommend a combination of primary and specialty palliative care, such as palliative care delivered by the primary oncology team and specialty care delivered by a palliative care team. This care is to be driven by assessment and referral to the appropriate provider and resources.[2, 10–12]

Unfortunately, current primary and specialty palliative care implementation in the treatment of advanced lung cancer is not well-described, hampering the development of effective cancer care delivery interventions and implementation strategies to address patients' unmet needs. To date, most research has focused only on outpatient specialty palliative care, namely describing its growth and implementation determinants (e.g., oncologist knowledge of specialty palliative care evidence, attitudes towards co-management with specialty

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palliative care).[4, 8, 13–15] Oncology providers' primary palliative care practices, including routine assessment of patients' symptom concerns, serious illness concerns, as well as collaboration with other providers, have not been described. Further, most research on palliative care implementation in advanced lung cancer is limited to academic medical centers and has focused on oncologists, limiting understanding of current palliative care implementation needs in community oncology settings where most patients receive their cancer care,[16, 17] palliative care resources are limited,[9, 18] and other clinicians such as advance practice providers and nurses may have an even greater role in managing patients' unmet needs.[19–21]

To identify potential intervention and implementation needs to address the supportive care and quality of life concerns of patients receiving treatment in community oncology practices, we aimed to describe: (1) community oncology clinicians' assessment of patients' potential palliative care needs; co-management with other specialties and providers; and stressfulness of delivering primary palliative care; and (2) community oncology clinicians' knowledge of specialty palliative care and barriers and facilitators to referrals. As an exploratory objective, we assessed differences in clinicians' primary and specialty palliative care practices based on clinician type (oncologist/advance practice provider vs. oncology nurse).

Materials and Methods

Study Design

Between August 2020 and May 2021, we surveyed clinicians from a network of 20 independent community-based oncology practices in Kentucky and surrounding regions. Most practices in the network are based in a rural-designated county or serve neighboring rural counties and treat fewer than 500 newly diagnosed cancers a year. Practices with local capacity for research had a site principal investigator and study coordinator to administer surveys. Those without local research capacity relied on a centralized study team to administer surveys remotely. All eligible clinicians were recruited via email through REDCap® or in-person. Clinicians reviewed study information sheets and provided informed consent before completing the survey. Written documentation of informed consent was waived for this study due to low study risk. Participants received $30. The University of Kentucky Medical Institutional Review Board approved this study (#55171).

Participants

Clinician inclusion criteria included: English speaking; age 18 years or older; physician, nurse, physician assistant, or nurse practitioner who routinely provides cancer care to advanced stage lung cancer patients; in practice at the clinic for at least 6 months.

Measures

Sociodemographic Factors. Clinicians self-reported sociodemographic, professional (e.g., years in practice, training), and caseload information.

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Primary Palliative Care Practices.

Assessment Practices. Clinicians reported how often in their everyday practice with advanced lung cancer patients they ask about physical (four items; e.g., “pain concerns”), psychosocial (three items; e.g., “psychological concerns such as emotional concerns or coping”), financial (two items; e.g., “insurance concerns”), and prognostic and serious illness concerns (6 items; e.g., “what they would worry most about if they were to get sicker”). Items were responded to on a scale of 0 = *almost never* to 4 = *almost always*. For analysis, we examined the proportion of clinicians who reported “almost always” asking patients about at least one concern in each potential domain of unmet care needs (e.g., psychosocial, physical), in addition to the frequency with which each concern was assessed.

Collaboration and Referral Practices. Clinicians reported how often they collaborate with other 16 other healthcare providers (e.g., social worker, occupational therapist, nutritionist) to support patients with advanced lung cancer. Response options included: *never*, *occasionally*, *often*, or *not available*. Clinicians were also asked how often they routinely referred seriously ill patients to palliative care at least 6 months before death and to hospice at least 30 days before death. Response options included 0 = *almost never* to 4 = *almost always*.

Perceived Stressfulness of Primary Palliative Care. Clinicians answered seven items assessing the perceived stressfulness of discussing severe physical symptoms, emotions, prognosis, advance directives, religious/spiritual beliefs, caregiver concerns, and breaking bad news with patients. Response options included 1 = *not at all stressful* to 5 = *extremely stressful*. Items were modified from the Palliative Care Attitudes Scale,[22] with additional investigator-generated items based on the literature.

Specialty Palliative Care.

Perceived Ease of Access to Palliative Care Providers. Clinicians were asked whether they had easy access to palliative care providers for referrals (yes/no).

Palliative Care Knowledge and Misconceptions. Items from the Health Information National Trends Survey 5,[23] assessed clinician knowledge of palliative care (e.g., “I’ve never heard of it,” I know a little bit about palliative care,” or “I know what palliative care is and could explain it to someone else”) and misconceptions (e.g., “Accepting palliative care means giving up”). Items were responded to on a Likert-type scale with 1 = *strongly disagree* to 4 = *strongly agree*. “Don’t know” responses were allowed. Failure to strongly disagree with a misconception was considered holding that misconception for analysis. Clinicians were also asked questions about the evidence for palliative care in metastatic lung cancer (e.g., “Are there sufficient data in the literature to support the benefit of early palliative care?”).[4]

Specialty Palliative Care Attitudes. To ensure uniform understanding, clinicians were provided with a description of specialty palliative care (i.e., “non-hospice”)[24, 25] (see Appendix) prior to answering subsequent questions. Clinicians were not allowed to go back and change answers to their previous survey responses. They completed modified versions

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of the cognitive and behavioral subscales of the Palliative Care Attitudes Scale (PCAS) to assess their beliefs about the benefits of specialty palliative care (e.g., "Do you think providing non-hospice palliative care would help your patients' physical quality of life?") and the likelihood that their patients would use the service. Responses were on a five-point Likert-type scale with varied anchors. Cognitive and behavioral subscales were calculated by summing items, with higher scores indicating more positive attitudes towards non-hospice palliative care. Subscales showed excellent internal reliability (Cronbach's α "Cognitive" = .87; "Behavioral" = .89).

Specialty Palliative Care Barriers and Facilitators. Clinicians were instructed to assume their healthcare center had access to specialty palliative care and asked to rate how much various factors would be a barrier or facilitate a referral. Barriers and facilitators were informed by the literature and Michie's Behavior Change Wheel.[4, 5, 26–28] Facilitators were reported on a Likert-type scale of 1 = *very unlikely* to 5 = *very likely*. For analysis, facilitator responses were collapsed to *very unlikely*/*unlikely*/*neutral* = not a facilitator and *likely* or *very likely* = facilitator. Similarly, barriers were reported on a Likert-type scale of 1 = *not at all a barrier* to 5 = *very much a barrier*. For analysis, barrier responses were collapsed to *not at all*/*slight barrier* = not a barrier, *somewhat*/*moderate* = *barrier*, or *very much a barrier* = major barrier.

Analysis

We computed means and standard deviations for continuous/interval variables and percentages for categorical variables. Bivariate tests (chi-square or Fisher's exact tests for categorical outcomes and two-sample t-tests for continuous outcomes) explored palliative care outcomes within provider type (MDs/Advance Practice Providers vs. Nurses); *p*-values are not reported for these exploratory analyses.

Results

Study Sample

Fifteen of 20 (80%) community practices contacted responded, of which 14 enrolled clinicians. The mean number of potentially eligible clinicians identified per practice was 5.1 (range = 3–13). 77 clinicians were identified as eligible and invited to participate, of which 48 (62.3%) completed the survey. The average clinician response rate at each practice was 63.1%. One clinician who participated was later determined to be ineligible due to being a palliative care physician and removed from analysis.

The majority (72.3%) of clinicians worked in a rural county per Rural-Urban Community Area Codes (U.S. Department of Agriculture Economic Research Service, 2010 RUCA Codes; Table 1). All but two were practicing in a Commission on Cancer accredited hospital. Over half had been at their institution for five years or fewer. Most (82.9%) had been in practice six or more years and treated between 1–20 advanced stage lung cancer patients a week. Average clinician age was 45.98 (SD = 10.22 years); 74.5% were female; 29.8% were oncologists; 55.3% were nurses. Among oncologists, 9 (64.3%) had palliative care training during residency or fellowship.

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Primary Palliative Care Practices

Assessment Practices. 74.5% (n = 35) reported "almost always" asking about at least one physical concern, 42.6% (n = 20) at least one psychosocial, 40.4% prognostic and serious illness, and 21.3% (n = 10) financial. Figure 1a shows the frequency with which clinicians reported asking about each concern. Comorbidity management was the least often assessed physical concern (6.4% "rarely," 25.5% "sometimes"). Spiritual/religious and informal caregiver concerns were the least often assessed psychosocial concern (27.6% "almost never" or "rarely" discuss spiritual/religious concerns; 4.3% "rarely" and 32.6% "sometimes" assess caregiver concerns). Over 30% reported "almost never" or "rarely" asking patients who they would like to make healthcare decisions for them, what they would worry about most if they were to get sicker, or to complete an advance directive. Insurance concerns were the least often assessed financial concern (2.1% "almost never," 25.5% "rarely" assess). A higher percentage of nurses than MDs/APPs reported "almost always" asking patients about at least one prognostic and serious illness concern (53.8% vs. 23.8%, respectively).

Collaboration Practices. The providers clinicians most often reported "never" collaborating with during advanced lung cancer care included: psychologist (57.4%), psychiatrist (55.3%), tobacco treatment specialist (34.0%), speech therapists (31.9%), and chaplains (25.5%) (Figure 1b; note: "Not available" was a response option). The providers clinicians most often reported "often" collaborating with included: pharmacists (68.1%), social workers (59.6%), primary care providers (57.4%), and palliative care specialists (39.3%). A higher percentage of MDs/APPs than nurses reported "often" collaborating with a palliative care specialist (52.4% vs. 26.9%, respectively).

Perceived Stressfulness of Primary Palliative Care (Online Only). Clinicians rated discussing caregiver concerns as one of the least stressful aspects of care (0% reported it as "very" or "extremely stressful"; 14.9% reported it as "somewhat stressful"). Breaking bad news was rated as the most stressful aspect of care (34.0% reported it as "very" or "extremely" stressful), though discussing prognosis was also reported as stressful to many (17.0% rated it as "very" or "extremely" stressful). A higher percentage of nurses vs. MDDs/APPs reported discussing patients' religious/spiritual beliefs was "not at all stressful" (65.4% vs. 14.3%, respectively).

Specialty Palliative Care

Palliative Care Knowledge and Misconceptions. 85.1% (n = 40) reported they knew what palliative care was and thought they could explain it. The remainder (14.9%) reported they knew a little bit about it. Self-perceived palliative care knowledge was not significantly different by clinician type (MD/APP vs. nurse, $p = .436$). Roughly 30% (n = 14) endorsed at least one palliative care misconception. The most common was that a patient would need to stop cancer treatment if they accepted palliative care (23.4%), that palliative care was the same as hospice (14.9%), or that using palliative care meant giving up (13.6%). Misconceptions were not different based on clinician type (*p's* .495–1.00). Fewer than half of clinicians (48.9%; n = 23) reported they had observed that palliative care could improve quality of life and prolong survival. 38.3% reported they had observed that palliative care

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could improve quality of life, but not prolong survival; 12.8% were unsure. 21.2% (n = 10) reported there was not definitive evidence in the literature to support the benefit of early palliative care; 36.2% (n = 17) reported a patient with metastatic lung cancer should only be referred to palliative care early in their disease course sometimes and 2.1% reported they should only be referred if they ask. A smaller percentage of nurses compared to MDs/APPs reported there was sufficient evidence to support the benefit of early palliative care (69.2% vs. 90.5%, respectively). A smaller percentage of nurses compared to MDs/APPs reported most patients with metastatic lung cancer should be always be referred to palliative care early in their disease course (42.3% vs. 85.7%, respectively).

Specialty ("non-hospice") Palliative Care Attitudes. Clinicians reported positive attitudes overall towards specialty palliative care once differentiated from hospice on the modified Palliative Care Attitudes Scale (Cognitive subscale M = 12.36; SD = 2.11; range = 8–15; Behavioral subscale M = 9.53, SD = 2.37; range = 4–14). On the cognitive subscale, roughly half of clinicians (51.1%, n = 24) reported that providing non-hospice palliative care would help "a great deal" with patients' physical quality of life, less than half (42.6%, n = 20) thought it would help "a great deal" with patients' feelings of sadness and depression, and fewer than a quarter (23.4%, n = 11) thought it would help "a great deal" to prolong patients' lives. On the behavioral subscale, 40.43% (n = 19) of clinicians believed that patients would be "completely" or "very likely" to go to non-hospice palliative care appointments on a monthly basis, 38.30% (n = 18) believe patients would be "completely" or "very likely" to go to a palliative care visit with other providers (e.g., palliative care physician), and 36.17% (n = 17) reported that patients would be "completely" or "very likely" to schedule the appointment as soon as possible. PCAS scores were not significantly different based on clinician type (p's = .308 - .941).

Barriers to Specialty Palliative Care. The most common barrier to specialty palliative care referrals was fear a referral would send the wrong message to patients (76.6%; Motivation), followed by concern about burdening patients with additional appointments (53.2%; Motivation), lack of structured referral process (53.2%; Opportunity), and lack of time to assess patients' palliative care needs (42.6%; Opportunity; Figure 2a). Fear a referral would send the wrong message (10.6%), lack of structured referral process (10.6%), and concern about burdening patients with additional appointments (8.5%) were the most common "major" barriers. Barriers were not significantly different based on clinician type except for: lack of knowledge of what palliative care offers (34.6% of nurses vs. 4.8% of MDs/APPs reported as a barrier);fear the referral would discourage a patient from completing treatment (34.6% of nurses vs. 4.8% of MDs/APPs reported as a barrier). Further, a higher percentage of nurses vs. MDs/APPs reported lack of confidence discussing palliative care with patients as a barrier (26.9% vs. 9.5%,respectively).

Facilitators to Specialty Palliative Care. In terms of patient characteristics, the most common facilitators were uncontrolled pain (93.6%) and weak support system (93.6%), poor performance status (87.2%; Figure 2b). The most common other facilitators were a patient requesting a referral (93.6%; Incentivization), followed tools to identify patients in need of palliative care (87.2%), and ease of referral (84.1%; Environment). The most common "very

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likely" facilitator was a patient requesting a referral (78.7%; Incentivization), followed by a patient having uncontrolled pain (63.8%), and ease of referral (61.7%; Environment). A higher percentage of MDs/APPs reported a weak support system would be a very likely facilitator to palliative care referral (71.4% vs. 34.6%, respectively), as would ease of referral (81.0% vs. 46.2%).

Discussion

Addressing the rural and underserved supportive care needs and quality of life concerns of patients undergoing treatment for advanced lung cancer requires well-coordinated primary and specialty palliative care, especially in rural and community-based oncology clinics where specialty providers are scarce. Based on the literature and an implementation framework (Michie's Behavior Change Wheel), we systematically described community oncology clinicians' primary palliative care practices and factors influencing specialty palliative care implementation. To inform interventions, we also explored how practices and implementation factors might vary by clinician (MDD/APP vs. nurse). Results suggest a need for implementation strategies that will improve routine assessment of patients' prognostic understanding and advanced illness needs (perhaps especially among MDs/APPs); increase collaboration with providers who can address functional concerns and health behaviors; improve clinician knowledge about specialty palliative care; and reduce specialty palliative care implementation barriers of clinician fear of patients' reactions to referral and lack of systematic processes to identify unmet palliative care needs and facilitate referrals.

Our results suggest many of the core components of palliative care needed to achieve the benefits observed in its clinical trials[10, 12, 29, 30] are not being delivered to advanced lung cancer patients in the community oncology setting. For example, our study suggests that while physical supportive care needs such as pain are likely to be queried, care needs related to patients' prognostic understanding and advance care planning are not. This is concerning, especially as patients' prognostic understanding tends to be poor and as prognostic and advance care planning discussions were identified as a key active ingredient in Temel et al.'s landmark early palliative care trial. Interestingly, our exploratory analyses suggested nurses may be more likely to have these conversations than MDs/APPs. While this result needs to be replicated in a larger sample, it is possible nurses assume this role based on their conception that oncologists are not having these conversations; because the conversation naturally arises when discussing other patient and caregiver concerns (e.g., distress); or because the care teams have designated certain topics to specific team members. Future research should describe how prognostic conversations occur in community oncology (with whom, when, and their nature) and the support needed to assess patients' prognostic understanding and integrate these conversations into clinical practice, especially as this was rated as one of the most stressful aspects of primary palliative care in our sample. Several existing trainings and tools could be leveraged to support implementation of this critical aspect of primary palliative care.[32–34]

Palliative care – whether "primary" or "specialty" –should be inherently interdisciplinary, leveraging different team members to address patient and family/caregiver supportive

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care needs and quality of life concerns.[10, 12, 30] Results suggest community oncology clinicians are most likely to routinely collaborate with pharmacists, social workers, primary care providers and dieticians in caring for advanced lung cancer patients and less likely to routinely collaborate with palliative care specialists, chaplains, financial counselors, occupational and physical therapists, and tobacco treatment specialists. Greater integration of "survivorship" providers (e.g., occupational and physical therapists, tobacco treatment specialists) could further address patients' functional concerns and health behaviors, which are increasingly salient and part of comprehensive palliative care in the current therapeutic landscape.[30]

In addition to primary palliative care, we assessed factors related to outpatient specialty palliative care implementation. This enabled us to describe the current knowledge base pertaining to specialty palliative care and also to identify top barriers and facilitators to implementing specialty palliative care after clinicians had a more uniform understanding of what it was. While most clinicians in this study believed they knew what palliative care was, a meaningful minority (14–23%) endorsed palliative care misconceptions such as that patients could not be on treatment and receive palliative care. Further, 21% did not think there was sufficient evidence to support the benefit of early palliative care. Exploratory analyses suggested misconceptions were similar among MDs/APPs and nurses; however, nurses appeared more likely to report there was insufficient evidence for the benefit of early palliative care. Although oncologists place referrals to palliative care, nurses are a trusted source of information for patients and may spend more time counseling patients. Thus, it is critical they understand the evidence for early palliative care and can encourage patients to avail themselves of this service, especially if they are more likely to have prognostic and serious illness conversations with patients (as our results suggested).

After being provided with a definition of specialty palliative care, the most commonly endorsed stated barrier to its implementation was fear a referral would send the wrong message to patients. Over 75% endorsed this barrier, considerably more than what Feld et al. observed in a predominantly academic sample (38%).[4] Nurses appeared more likely to endorse related barriers such as fear a referral might discourage a patient from completing treatment or being unsure what palliative care offers. These results suggest the entire oncology team needs to understand and be integrated into specialty palliative care. However, one of the best ways to address clinicians' fear of referral might be patient empowerment—a component that is not often integrated into palliative implementation interventions. Indeed, the strongest facilitator clinicians reported in this study was for patients to request a referral. Given high levels of palliative care misconceptions among patients[6, 7] and clinician fear about discussing palliative care with patients, interventions (e.g., palliative care screening tools, referral templates, clinician education) that do not help educate patients about what palliative care is and empower a patient to request a referral are likely to be ineffective.

Limitations

This study was limited by a small sample size, precluding ability to draw conclusions about differences by clinician type. However, it is unique in its assessment of community oncology clinician perspectives and assessment of both primary and specialty palliative care

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practices and determinants, use of standardized measures of palliative care knowledge, and an implementation and behavior change framework. This study occurred during the height of onset of COVID-19, which could have reduced response rates; however, we do expect this significantly affected study findings.

Conclusions

Interventions that help oncology clinicians better assess and co-manage psychosocial and serious illness concerns are needed to improve primary palliative care in community oncology practices. As specialty palliative care becomes more available, addressing barriers to its implementation will require system changes to help identify unmet palliative care needs, facilitate referrals, and coordinate care, as well as strategies to educate and empower entire oncology teams (MDs, APPs, nurses) and their patients in utilizing this critical resource.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Hoerger M, Wayser GR, Schwing G, Suzuki A, Perry LM. Impact of interdisciplinary outpatient specialty palliative care on survival and quality of life in adults with advanced cancer: a meta-analysis of randomized controlled trials. Annals of Behavioral Medicine. 2019;53(7):674–685. [PubMed: 30265282]
2. Smith TJ, Temin S, Alesi ER, et al. American Society of Clinical Oncology provisional clinical opinion: the integration of palliative care into standard oncology care. Journal of clinical oncology. 2012;
3. Kayastha N, LeBlanc TW. Why Are We Failing to Do What Works? Musings on Outpatient Palliative Care Integration in Cancer Care. JCO Oncology Practice. 2022;18(4):255–257. doi:10.1200/op.21.00794 [PubMed: 34936378]
4. Feld E, Singhi EK, Phillips S, Huang L-C, Shyr Y, Horn L. Palliative care referrals for advanced non–small-cell lung cancer (NSCLC): patient and provider attitudes and practices. Clinical Lung Cancer. 2019;20(3):e291–e298. [PubMed: 30862422]
5. Dunn S, Earp MA, Biondo P, et al. Oncology Clinicians' Challenges to Providing Palliative Cancer Care—A Theoretical Domains Framework, Pan-Cancer System Survey. Current Oncology. 2021;28(2):1483–1494. [PubMed: 33918837]

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6. McLouth LE, Borger T, Bursac V, et al. Palliative care use and utilization determinants among patients treated for advanced stage lung cancer care in the community and academic medical setting. Supportive Care in Cancer. 2023;31(3):190. [PubMed: 36847880]
7. McLouth LE, Gabbard J, Levine BJ, et al. Prognostic Awareness, Palliative Care Use, and Barriers to Palliative Care in Patients Undergoing Immunotherapy or Chemo-Immunotherapy for Metastatic Lung Cancer. Journal of Palliative Medicine. 2023;
8. Hui D, De La Rosa A, Chen J, et al. State of palliative care services at US cancer centers: An updated national survey. Cancer. Jan 1 2020;126(9):2013–2023. doi:10.1002/cncr.32738 [PubMed: 32049358]
9. Center CtAPCatNPCR. America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals. 2019.
10. Bakitas MA, El-Jawahri A, Farquhar M, et al. The TEAM Approach to Improving Oncology Outcomes by Incorporating Palliative Care in Practice. Journal of Oncology Practice. 2017;13(9):557–566. doi:10.1200/jop.2017.022939 [PubMed: 28898605]
11. Hui D, Heung Y, Bruera E. Timely palliative care: Personalizing the process of referral. Cancers. 2022;14(4):1047. [PubMed: 35205793]
12. Hui D, Hannon BL, Zimmermann C, Bruera E. Improving patient and caregiver outcomes in oncology: Team-based, timely, and targeted palliative care. CA: a cancer journal for clinicians. 2018;68(5):356–376. [PubMed: 30277572]
13. Hausner D, Tricou C, Mathews J, et al. Timing of Palliative Care Referral Before and After Evidence from Trials Supporting Early Palliative Care. Oncologist. 2021;26(4):332–340. doi:10.1002/onco.13625 [PubMed: 33284483]
14. Hui D, Kilgore K, Park M, et al. Pattern and Predictors of Outpatient Palliative Care Referral Among Thoracic Medical Oncologists. Oncologist. Oct 2018;23(10):1230–1235. doi:10.1634/theoncologist.2018-0094 [PubMed: 29895629]
15. Rosenblum RE, Rogal SS, Park ER, et al. National Survey Using CFIR to Assess Early Outpatient Specialty Palliative Care Implementation. Journal of Pain and Symptom Management. 2023/03/01/ 2023;65(3):e175–e180. doi:10.1016/j.jpainsymman.2022.11.019 [PubMed: 36460231]
16. Green LA, Fryer GE, Yawn BP, Lanier D, Dovey SM. The Ecology of Medical Care Revisited. New England Journal of Medicine. 2001;344(26):2021–2025. doi:10.1056/nejm200106283442611 [PubMed: 11430334]
17. Atkins GT, Kim T, Munson J. Residence in Rural Areas of the United States and Lung Cancer Mortality. Disease Incidence, Treatment Disparities, and Stage-Specific Survival. Ann Am Thorac Soc. Mar 2017;14(3):403–411. doi:10.1513/AnnalsATS.201606-469OC [PubMed: 28118039]
18. Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. The Lancet. 2018;391(10128):1391–1454.
19. Brant J, Fink RM. Role of the Nurse in the Palliative Care Community. In: Silbermann M, ed. Palliative Care for Chronic Cancer Patients in the Community: Global Approaches and Future Applications. Springer International Publishing; 2021:39–48.
20. Bakitas M, Allen Watts K, Malone E, et al. Forging a New Frontier: Providing Palliative Care to People With Cancer in Rural and Remote Areas. J Clin Oncol. Mar 20 2020;38(9):963–973. doi:10.1200/jco.18.02432 [PubMed: 32023156]
21. Dahlin C Palliative Care: Delivering Comprehensive Oncology Nursing Care. Semin Oncol Nurs. Nov 2015;31(4):327–37. doi:10.1016/j.soncn.2015.08.008 [PubMed: 26525732]
22. Perry LM, Hoerger M, Malhotra S, Gerhart JI, Mohile S, Duberstein PR. Development and Validation of the Palliative Care Attitudes Scale (PCAS-9): A Measure of Patient Attitudes Toward Palliative Care. Journal of Pain and Symptom Management. 2020/02/01/ 2020;59(2):293–301.e8. doi:10.1016/j.jpainsymman.2019.09.008 [PubMed: 31539604]
23. Nelson DE, Kreps GL, Hesse BW, et al. The Health Information National Trends Survey (HINTS): development, design, and dissemination. J Health Commun. Sep-Oct 2004;9(5):443–60; discussion 81–4. doi:10.1080/10810730490504233 [PubMed: 15513791]
24. Kelley AS, Meier DE. Palliative Care — A Shifting Paradigm. New England Journal of Medicine. 2010;363(8):781–782. doi:10.1056/NEJMe1004139 [PubMed: 20818881]

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25. Beasley A, Bakitas MA, Edwards R, Kavalieratos D. Models of non-hospice palliative care: a review. Ann Palliat Med. Feb 2019;8(Suppl 1):S15–s21. doi:10.21037/apm.2018.03.11 [PubMed: 29860852]
26. Michie S, Van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implementation science. 2011;6(1):1–12. [PubMed: 21208425]
27. Michie S, Johnston M, Abraham C, Lawton R, Parker D, Walker A. Making psychological theory useful for implementing evidence based practice: a consensus approach. BMJ Quality & Safety. 2005;14(1):26–33.
28. Charalambous H, Pallis A, Hasan B, O'Brien M. Attitudes and referral patterns of lung cancer specialists in Europe to Specialized Palliative Care (SPC) and the practice of Early Palliative Care (EPC). BMC Palliative Care. 2014/12/16 2014;13(1):59. doi:10.1186/1472-684X-13-59 [PubMed: 25550683]
29. Hoerger M, Greer JA, Jackson VA, et al. Defining the elements of early palliative care that are associated with patient-reported outcomes and the delivery of end-of-life care. Journal of Clinical Oncology. 2018;36(11):1096. [PubMed: 29474102]
30. Temel JS, Petrillo LA, Greer JA. Patient-Centered Palliative Care for Patients With Advanced Lung Cancer. J Clin Oncol. Feb 20 2022;40(6):626–634. doi:10.1200/jco.21.01710 [PubMed: 34985932]
31. Helft PR, Chamness A, Terry C, Uhrich M. Oncology nurses' attitudes toward prognosis-related communication: a pilot mailed survey of oncology nursing society members. Oncol Nurs Forum. Jul 2011;38(4):468–74. doi:10.1188/11.Onf.468-474 [PubMed: 21708537]
32. CAPC. Accessed June 20, 2023. https://www.capc.org/training/communication-skills/
33. Leong M, Shah M, Smith TJ. How to Avoid Late Chemotherapy. Journal of Oncology Practice. 2016;12(12):1208–1210. doi:10.1200/jop.2016.017137 [PubMed: 27650845]
34. Epstein AS, Kakarala SE, Reyna VF, et al. Development of the Oncolo-GIST ("Giving Information Strategically & Transparently") Intervention Manual for Oncologist Skills Training in Advanced Cancer Prognostic Information Communication. Journal of Pain and Symptom Management. 2021/07/01/ 2021;62(1):10–19.e4. doi:10.1016/j.jpainsymman.2020.11.023 [PubMed: 33253786]
35. Robinson CA, Pesut B, Bottorff JL, Mowry A, Broughton S, Fyles G. Rural palliative care: a comprehensive review. Journal of Palliative Medicine. 2009;12(3):253–258.
36. Andrykowski MA, Burris JL. Use of formal and informal mental health resources by cancer survivors: differences between rural and nonrural survivors and a preliminary test of the theory of planned behavior. Psycho-Oncology. 2010;19(11):1148–1155. doi:10.1002/pon.1669 [PubMed: 20017114]
37. Conduit C, Thompson M, Thomas R, Nott L, Wuttke M. Implementing 'Goals of Care' discussion and palliative care referral for patients with advanced lung cancer: an outpatient-based pilot project. Internal Medicine Journal. 2021;51(4):540–547. doi:10.1111/imj.14817 [PubMed: 32202060]
38. Sridharan K, Paul E, Stirling RG, Li C. Impacts of multidisciplinary meeting case discussion on palliative care referral and end-of-life care in lung cancer: a retrospective observational study. Intern Med J. Sep 2021;51(9):1450–1456. doi:10.1111/imj.15215 [PubMed: 33463032]
39. Sedhom R, Gupta A, Shah M, et al. Oncology Fellow-Led Quality Improvement Project to Improve Rates of Palliative Care Utilization in Patients With Advanced Cancer. JCO Oncol Pract. Aug 2020;16(8):e814–e822. doi:10.1200/jop.19.00714 [PubMed: 32339469]
40. Look Hong NJ, Liu N, Wright FC, et al. Assessing the Impact of Early Identification of Patients Appropriate for Palliative Care on Resource Use and Costs in the Final Month of Life. JCO Oncol Pract. Aug 2020;16(8):e688–e702. doi:10.1200/jop.19.00397 [PubMed: 32196422]
41. Reville B, Reifsnyder J, McGuire DB, Kaiser K, Santana AJ. Education and referral criteria: impact on oncology referrals to palliative care. J Palliat Med. Jul 2013;16(7):786–9. doi:10.1089/jpm.2012.0487 [PubMed: 23510168]
42. Hui D, Titus A, Curtis T, et al. Implementation of the Edmonton Symptom Assessment System for Symptom Distress Screening at a Community Cancer Center: A Pilot Program. Oncologist. Aug 2017;22(8):995–1001. doi:10.1634/theoncologist.2016-0500 [PubMed: 28476945]

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43. Mittmann N, Liu N, MacKinnon M, et al. Does early palliative identification improve the use of palliative care services? PLoS One. 2020;15(1):e0226597. doi:10.1371/journal.pone.0226597 [PubMed: 32005036]

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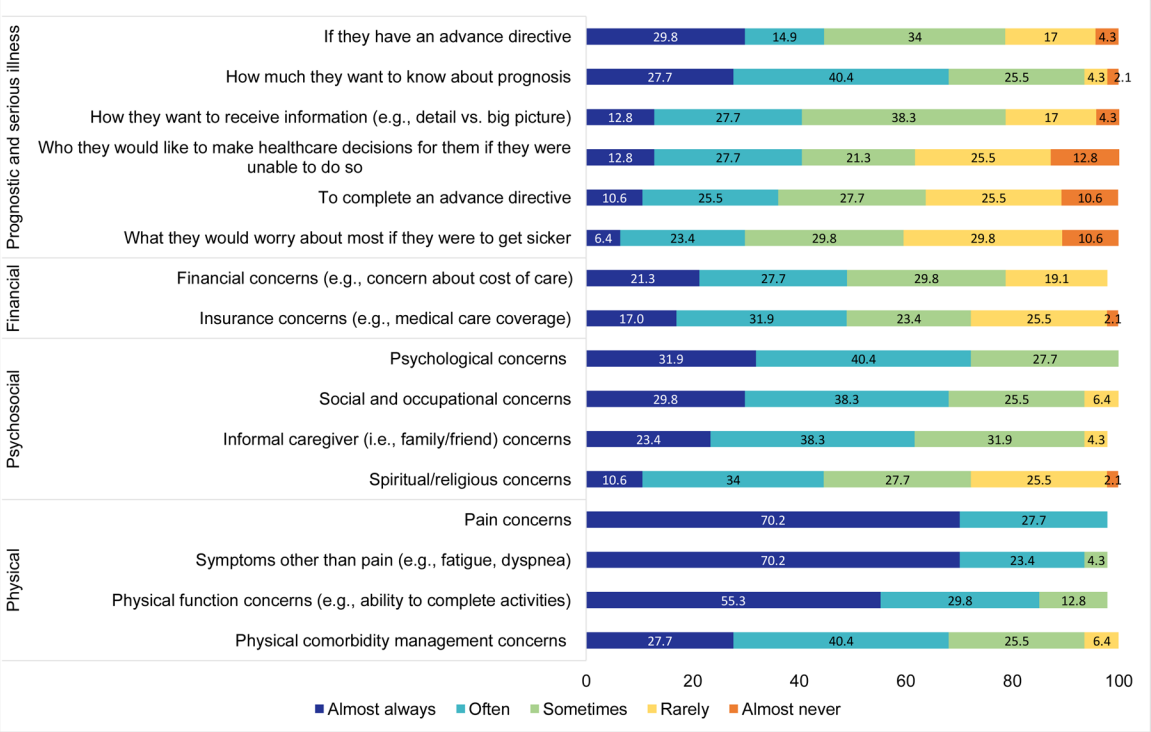

Figure 1a.

Clinician-Reported Frequency of Assessing Primary Palliative Care Concerns with Advanced Lung Cancer Patients (N = 47; %)

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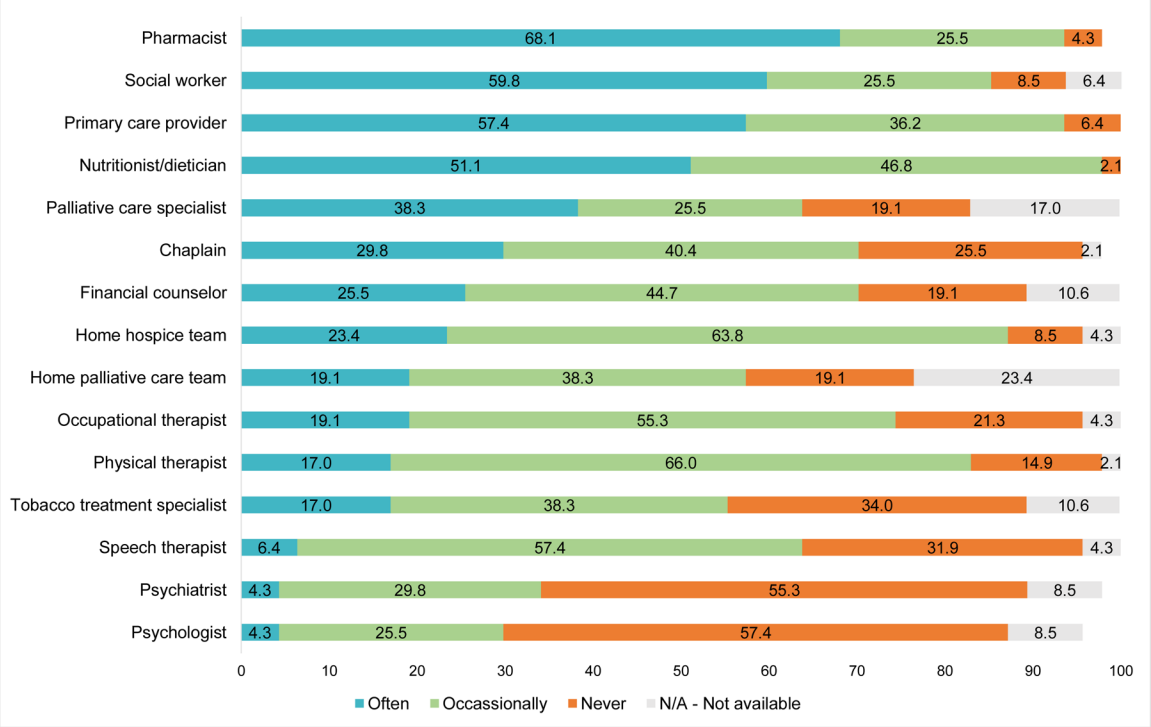

Figure 1b.

Community Oncology Clinicians' Collaboration Practices for Patients with Advanced Lung Cancer Patients (N = 47)

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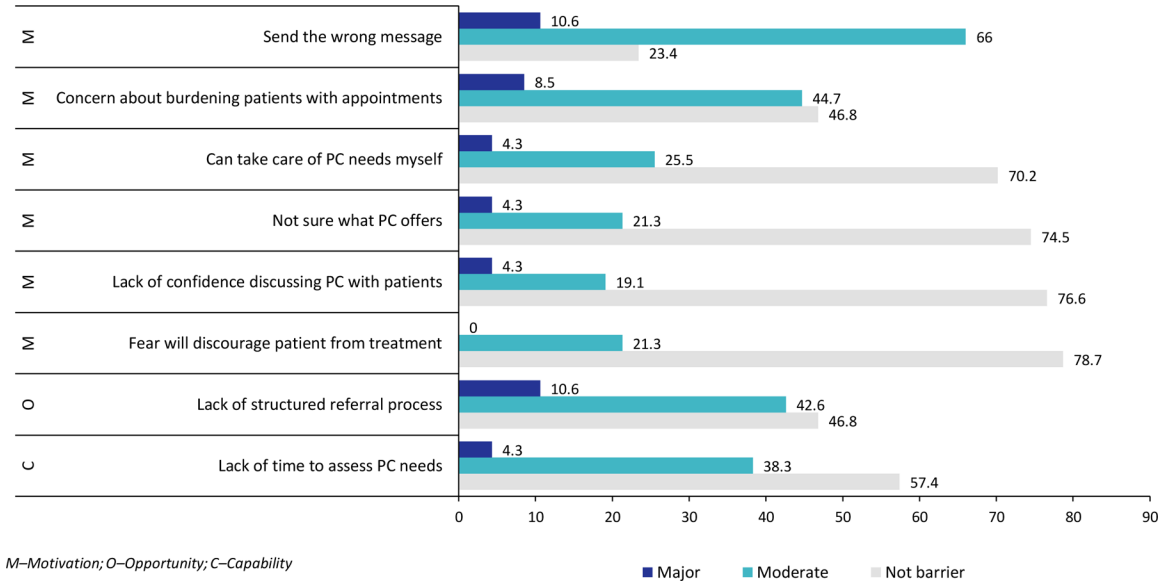

Figure 2a.

Proportion of Clinicians Endorsing Each Potential Barrier to Referring Patients to Specialty Palliative Care (N = 47)

Note. “PC” = palliative care. “Capability,” “Opportunity” and “Motivation,” refer to behavioral determinants from the Capability Opportunity Motivation-Behavior System in the Behaviour Change Wheel. “Capability” refers to psychological and physical capacity to refer a patient to palliative care. “Opportunity” refers to external factors that determine a referral such as workflow. “Motivation” refers to cognitions and emotions that determine a referral.

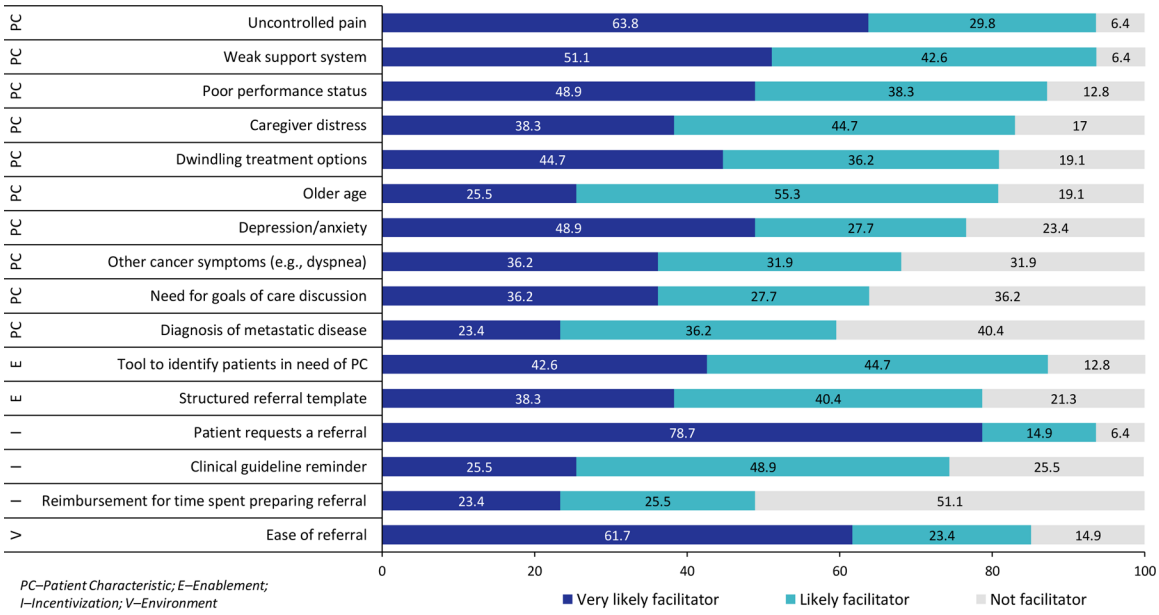

Figure 2b.

Proportion of Clinicians Endorsing Each Potential Facilitator to Referring Patients to Specialty Palliative Care (N =47)

Note. Intervention functions informed by the Behaviour Change Wheel.

"Enablement" refers interventions that increase capability and opportunity for palliative care referral beyond education. "Incentivization" refers to interventions that create an expectation of a reward. "Environmental Restructuring" refers to changing the clinical workflow context.

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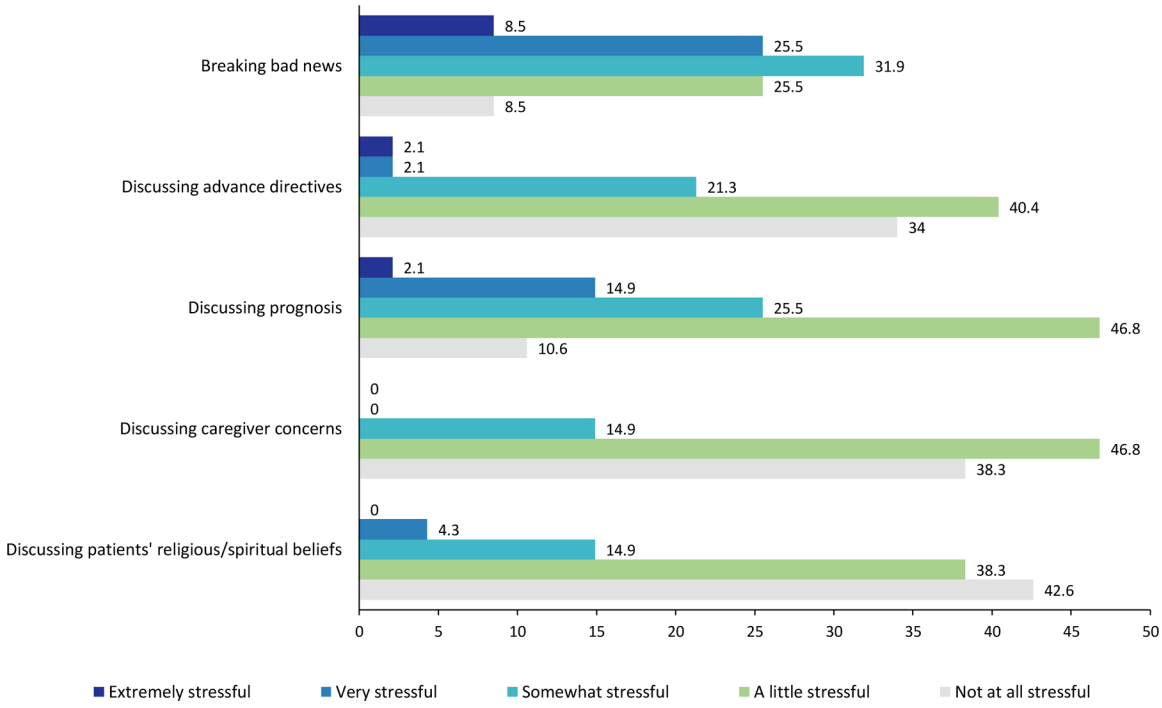

Online Figure.

Proportion of Clinicians Reporting Stressfulness of Delivering Aspects of Primary Palliative Care (N = 47)

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Table 1.

Community Oncology Clinician Demographics (N = 47)

	n (%)
Rural county practice	34 (72.3)
Commission on Cancer accreditation classification	
Hospital Associate Cancer Program	11 (23.4)
Community Cancer Program	21 (44.7)
Comprehensive Community Cancer Program	13 (27.7)
Not yet accredited	2 (4.3)
Years at institution	
<1 year	3 (6.4)
1–5 years	20(42.6)
6–10 years	7 (14.9)
11–20 years	7 (14.9)
>20 years	10 (21.3)
Years in practice	
<1 year	1 (2.1)
1–5 years	16 (34.0)
6–10 years	5 (10.6)
11–20 years	10 (21.3)
>20 years	15 (31.9)
Age, Mean (SD); Range	45.98 (10.22); 25–67
Female	35 (74.5)
Clinician type	
Oncologist	14 (29.8)
Advanced practice provider	7 (14.9)
Nurse	26 (55.3)
Oncologist had palliative care training during residency or fellowship	9 (64.3)
Number of advanced stage lung cancer patients treated per week	
1–10	27 (57.4)
11–20	12 (25.5)
21–30	4 (8.5)
31–50	3 (6.4)
Missing	1 (2.1)