

ASSOCIATION OF COMMUNITY CANCER CENTERS

Examining Patient-Centered Small Cell Lung Cancer Care: PATIENT AND PROVIDER PERSPECTIVES

BACKGROUND INFORMATION

To uncover barriers in obtaining optimal care for patients with small cell lung cancer (SCLC), the Association of Community Cancer Centers (ACCC) conducted patient and provider surveys. The purpose of the surveys was to garner real-world insights into the factors that lead to delayed diagnoses and treatment, and poor symptom management of patients with SCLC.

The provider survey was developed by the Association of Community Cancer Centers (ACCC) and sent via direct email to providers between March and April 2022. A survey was also developed for patients with SCLC to impart additional context to the provider survey. The patient survey was developed by CE Outcomes, LLC, and reviewed by ACCC. Managing physicians and online support groups distributed the survey to patients between May and July 2022. Both surveys were submitted and received internal review board (IRB) exemptions. A follow-up survey was also conducted to better understand physicians' prescriptive treatment approaches for their patients with extensive-stage SCLC (ES-SCLC).

Provider and Patient Surveys

Of the 100 provider responses, 32 percent were physicians, 26 percent were advanced practice providers (APPs) or pharmacists, 27 percent were nurses or nurse navigators, and 15 percent were psychosocial support providers (PSS). Physicians identified equally to working in a community cancer program (34%), versus a private practice (34%). Work environment was similarly distributed among other provider types (APPs/pharmacists and nurse/nurse navigators). In contrast, psychosocial support providers were most commonly found working within a private or physician practice at 47 percent. The physician follow-up survey had a 41 percent response rate (13/32).

Of the 51 patients who responded, the median age was 40. Fifty-three percent (53%) were male, and 59 percent had limited-stage SCLC (LS-SCLC). Racial and ethnic breakup was as follows: 69 percent were White, 10 percent were Black/African American, and six percent (6%) were Asian/Asian American, Hispanic/Latinx, American Indian/Alaska Native, or Native Hawaiian/Pacific Islander. Forty-five percent (45%) of surveyed patients held private insurance, 33 percent were beneficiaries of Medicare, eight percent (8%) had Medicaid,

and two percent (2%) were under- or uninsured.

Diagnosis and Management of SCLC

Delays in the diagnosis of SCLC have been variably estimated due to the use of different parameters across studies. In a systematic review, the median time from symptom onset to diagnosis was estimated to be 69 days for patients with any stage of SCLC, and the median time from symptom onset to the first visit with a specialist was 33.3 days among patients with any type of lung cancer.¹ A US-based study not included in the systematic review, found that there was a median time of 52 days between the first clinic visit to treatment for patients with NSCLC (69% of cohort) or SCLC (31% of cohort).²

In the ACCC patient survey, patients reported they saw a median of three doctors for their symptoms prior to receiving their SCLC diagnosis. Given the rapid doubling time of SCLC, clinical presentation can be consistent with pulmonary inflammatory or infectious conditions, leading to delays in appropriate management.³ Providers reported that the top three contributors to a delay in SCLC diagnosis were biopsy confirmation or pathology results, patient access to care, and scheduling delays such as availability of office appointments (see Figure 1, page 4).

In a systematic review of lung cancer research, nine studies found an association between shorter wait times from diagnosis to treatment, and improved patient outcomes.¹ Additionally, a single-center study from the MD Anderson-Cooper Cancer Center in New Jersey found that SCLC stage at diagnosis was predictive of survival.⁴ Although the data are somewhat mixed, taken together, early diagnosis is critical to improve outcomes for patients with SCLC.

Currently, molecular profiling by next-generation sequencing (NGS) is recommended for only those patients with ES-SCLC who have never smoked or lightly smoked tobacco.⁵ Molecular profiling does not change the treatment approach, however, because targeted therapies that require the presence of gene mutation as identified by NGS are not yet approved for SCLC. Because of this, it is not surprising that 15 percent of APPs and 19 percent of physicians in the ACCC provider survey reported rarely/never ordering NGS for limited-stage SCLC patients.

The mean time from diagnosis of SCLC to treatment has been reported as 18 days.¹ In previously conducted research in SCLC care, factors associated with delayed time to treatment initiation included outpatient versus inpatient workup, number of diagnostic procedures, early- versus late-stage disease, and increasing age.⁶ Physicians and APPs reported in the ACCC survey that the major causes of significant delays in treatment for limited- and extensive-stage disease were insurance approval, biopsy confirmation, and staging evaluation (see Figure 2, page 5). Clinic infusion availability was reported as a cause for delay in treatment more frequently for extensive-stage disease, particularly by physicians.

Quality of Life

Providers indicated that quality of life (QOL) was an important factor in treatment decisions (see Figure 3, page 5). Most providers indicated that the role of QOL in decision-making is dependent on disease staging, and whether the treatment is considered curative or palliative. Providers also noted that a shared decision-making approach was important with consideration of the patient's stated preferences and goals. Providers measured QOL primarily through discussions with their patient. In this instance, a good QOL is considered to be the ability to continue activities of daily living (ADLs) or desired activities, achieve goals, and interact with family and friends. In the patient survey, respondents indicated that their QOL could be improved with assistance in overcoming the following challenges during treatment: management of their pain or any other unwanted symptoms, addressing their psychological wellbeing, help with logistical aspects of SCLC care, such as financial barriers and living situations, and addressing spiritual or existential suffering.

Disease Burden

Frequently, patients present with symptoms suggestive of widespread metastatic disease, such as weight loss, bone pain, and neurologic compromise. Increasing symptom burden has a negative impact on patients' quality of life.⁵ ACCC's patient survey found the most bothersome symptoms of SCLC were persistent cough (48%), loss of appetite (47%), chest pain or discomfort (45%), fatigue (43%), difficulty breathing or wheezing (36%), and hoarseness or difficulty speaking (30%) (see Figure 4, page 6).

TREATMENT PATTERNS AND REFERRALS

Limited-Stage SCLC

The provider survey used a case study to ask specific questions about treatment and management patterns for LS-SCLC. The case study patient had LS-SCLC with multiple involved nodes (see side bar). The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines[®]) specify concurrent RT and a platinum

agent plus etoposide as a preferred first-line treatment option for a patient with medically inoperable LS-SCLC.⁷ Consistent with this recommendation, most physicians (91%) and APPs (73%) would treat the case study patient with concurrent RT and chemotherapy (see Figure 5, page 7). The NCCN Guidelines[®] preferred recommendation for second- and subsequent-line treatment is clinical trial participation or a platinum-based doublet chemotherapy regimen. Rechallenging with the original or a similar platinum-based regimen should only be considered, however, if there has been a disease-free interval of three to six months.

Case Study: LS-SCLC

- JD: 69-year-old man with fatigue, weight loss, dry cough, shortness of breath
- 50-year history of tobacco use but quit 3 years ago
- Bronchoscopy showed right hilar mass with 4 right and 4 left lymph nodes involved
- PET-CT showed no distant disease
- Diagnosed with limited-stage SCLC

Referral to a Clinical Trial for LS-SCLC

Fifty-one percent (51%) of physicians and sixty-seven percent (67%) of APPs indicated they would either definitely or likely refer the case study patient for clinical trial participation (see Figure 6, page 7), depending on clinical trial availability. However, multiple barriers to clinical trial participation were identified by physicians, including lack of trial availability, lack of transportation or other logistical barriers, patient preference, narrow inclusion criteria, and need for more immediate treatment (see Figure 7, page 8). The primary reason for not referring to a clinical trial was that the provider would try the standard of care/first-line treatment first, or it was felt that a trial was not needed. In addition, not all providers had access to clinical trials in their practice.

Extensive-Stage SCLC

The NCCN Guidelines recommend preferred first-line treatment regimens for ES-SCLC include doublet chemotherapy with atezolizumab or durvalumab followed by atezolizumab or durvalumab maintenance, regardless of PD-L1 expression.⁷ In the follow-up survey, respondents reported that most of their patients (80%) with newly diagnosed ES-SCLC receive a platinum doublet plus atezolizumab or durvalumab as first-line therapy. Autoimmune disorders, prior allergies, and cost concerns were all reasons given by respondents for the 18 percent of their patients who receive chemotherapy alone as first-line therapy. Physicians in this cohort shared that an average of four percent (4%) of their patients did not receive any first-line treatment for ES-SCLC due to factors such as poor performance status, multiple comorbidities, and patients' decision to choose palliative care.

SCLC is highly sensitive to initial chemotherapy with good response rates, however most patients will relapse.⁸ As such, the survey also explored second and subsequent-line ES-SCLC treatment and management patterns. NCCN Guidelines preferred second-line regimens include platinum-based doublets or a clinical trial. Other recommended regimens include chemotherapy or immune checkpoint inhibitors. In the ACCC survey, 13 percent of physicians reported that less than or equal to 50 percent of their patients with ES-SCLC initiated second-line treatment at disease progression. Twenty percent (20%) of APPs reported that less than or equal to 50 percent of patients initiated second-line treatment at disease progression. In the follow-up survey, physicians reported that many factors are considered in whether they would recommend platinum-based rechallenge when choosing subsequent systemic therapy for patients with SCLC. These include degree and duration of first response, patient performance status and organ function, as well as number of comorbidities.

Data from the ACCC survey shows a potentially substantial portion of patients are not receiving second-line therapy (see Figure 8, page 8). Several barriers to second-line treatment initiation among patients with ES-SCLC were identified by physicians, with the most important being concerns about patient fitness, followed by concern about managing treatment-related adverse events, and the presence of multiple comorbidities. APPs reported a greater concern for comorbidities and managing treatment-related adverse events than physicians. They also reported concerns with lack of transportation, lack of a support system, and difficulty comprehending the diagnosis for patients. In a follow-up survey, physicians noted several key factors that would need to be present in new anti-cancer agents before they would consider recommending for second-line treatment to patients with ES-SCLC. Factors included fewer side effects, manageable cost, and high response rates with improved survival.

Patient Role in Decision Making

Overall, patients reported feeling that they make substantial contributions to final decisions regarding treatment selection. Twenty-seven percent (27%) of patients said that although their physician made the final decision, their opinion was considered, 27 percent said that they made the final decision but seriously considered the physician's opinion, 24 percent said the responsibility was shared, 14 percent indicated leaving all decisions to the physician, and eight percent reported that they made the decision.

Caregivers

Caregivers are frequently involved in treatment and care planning. Thirty-two percent (32%) of providers indicated that more than half of their patient cases involved a caregiver. Of

the patients who involve a caregiver, while the majority of communication regarding treatment and care is conducted with the patient, 41 percent of physicians and 35 percent of APPs said they had this conversation with the caregiver more than 50 percent of the time (see Figure 9, page 9). This suggests that most caregivers provide an important supportive role to patients with SCLC. Inclusion of caregivers at patient visits should be strongly considered, and caregivers should be included in communication, education, and the decision-making process.

SUPPORT SERVICES AND TRUSTED RESOURCES

Support and Ancillary Services

The ACCC survey found that APPs, nurses, and psychosocial support providers were more likely to provide education and information to patients, including an explanation of the diagnosis, answering questions, providing educational handouts and trusted internet resources, and providing referrals to supportive care services. These data highlight the importance of APPs as part of the care team, as they are the primary team member who provides patients with education and information about their diagnosis and treatment.

An important aspect of supportive care is referral to palliative care. The American Society of Clinical Oncology (ASCO) recommends that all inpatients and outpatients with advanced cancer be referred to dedicated palliative care services, preferably with an interdisciplinary team, early in their disease course.⁹ This recommendation is based on data from randomized controlled trials that demonstrated palliative care services improve quality of life, reduce rates of depression and depressed mood, and in some cases, prolong overall survival. Specific to SCLC, a single-center, retrospective study found that patients who received early palliative care demonstrated improved overall survival ($P=.01$), and a numerically lower median number of hospitalizations compared with delayed palliative care.¹⁰ A larger retrospective study of over 23,000 patients with lung cancer, including 18 percent with SCLC, found that palliative care improved survival when initiated between one month and one year after diagnosis (adjusted hazard ratio, 0.47; 95 % Confidence Interval, 0.45-0.49), but there was no improvement in survival if it was initiated after one year.¹¹

Regarding the case study patient presented in the survey, 31 percent of physicians, 58 percent of APPs, and 70 percent of nurses indicated they would make a direct referral to palliative care. Physicians reported, they typically refer patients to palliative or supportive care at various stages during treatment, including, after failure of multiple lines of therapy, upon first recurrence or refractory disease, at diagnosis, or when symptoms become difficult to manage or are uncontrolled. APPs were more likely

to refer their patients when symptoms became difficult to manage or after multiple lines of therapy (see Figure 10, page 9). These data highlight an opportunity to improve patient care, as palliative care is recommended to be initiated at earlier stages of the disease. Barriers that limit referral to palliative care were most commonly patient resistance, lack of understanding of the value or focus of palliative care, and the capacity of palliative care services.

Trusted Resources

An important part of oncology care is to support patients through their cancer journey, from diagnosis to survivorship. This includes education about their diagnosis and treatment. However, the ACCC survey found that, for the case study patient, 59 percent of physicians would provide an explanation of the patient’s diagnosis and what it means for them, 47 percent would provide materials or handouts about their diagnosis, 50 percent would answer all of the patient’s questions, and 22 percent would provide a list of trusted internet sources or patient advocacy organization for support (see Figure 11, page 10). APPs were more likely to provide this information to patients, but at least a quarter or more of APPs said that they would not. Patients reported this type of information is something they would like more of, including links to specific websites with accurate and updated information about SCLC (67%), paper pamphlets or handouts from their care team (63%), information about support groups, both social medical groups or local options (59%), information about smartphone and tablet applications (51%), and more information about

how national SCLC organizations or advocacy groups help patients (51%; see Figure 12, page 10). ACCC’s upcoming Comprehensive Care Initiative aims to help address this gap.

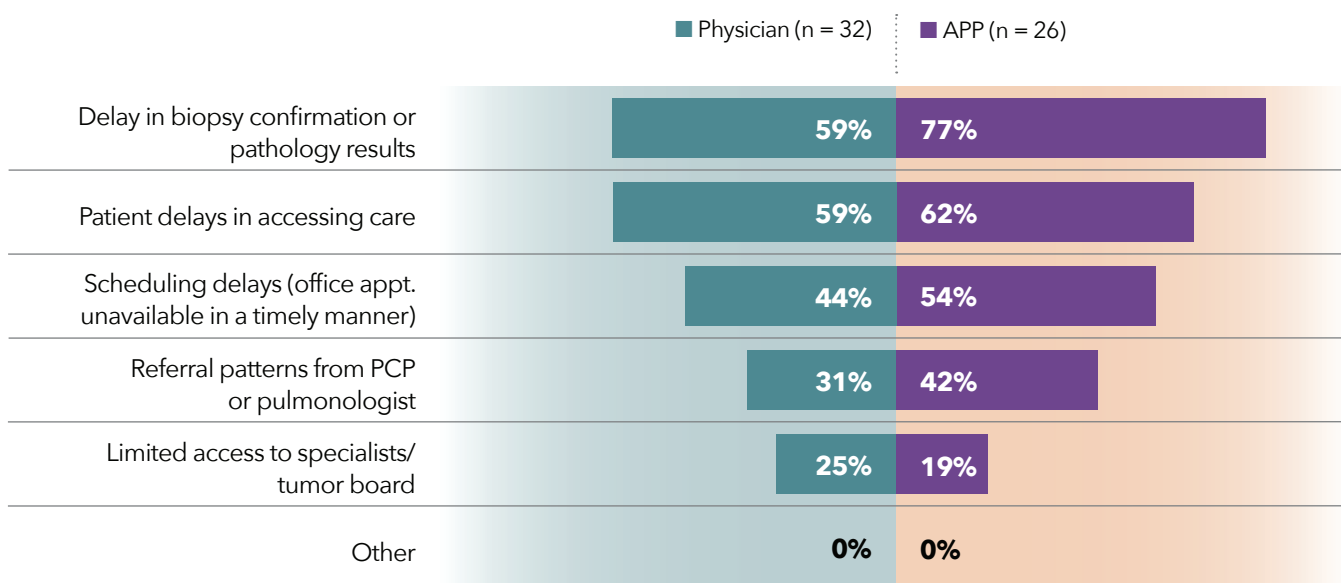
Patient Advocacy Groups

- LUNGeVity Foundation
- Cancer.Net
- GO2 Foundation for Lung Cancer
- American Cancer Society
- Cancer Support Community

CONCLUSION

The results from the provider and patient surveys identified several critical gaps in the management of SCLC, including barriers to access clinical trials, delayed referral to palliative and supportive care services. Additional areas of concern, as identified in other published studies and discussed by members of this project committee, include a need for earlier detection of SCLC when it is potentially curable, as well as the identification of new, more effective personalized therapies. NCCN recommends clinical trial participation as an important treatment option, particularly for second and subsequent-line therapy, yet a majority of providers reported a concern about the presence of barriers that prevent many patients from participating in trials. Moreover, although nearly all patients receive first-line treatment, many patients are not receiving second-line therapy and are not being referred to palliative or supportive care services during their SCLC journey, highlighting a critical gap in the overall management of SCLC. *(continued, page 11)*

FIGURE 1. Provider-Reported Reasons That Contribute to Delays in SCLC Diagnosis



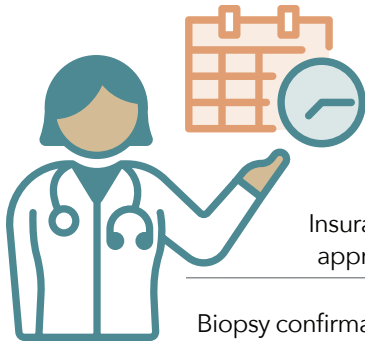
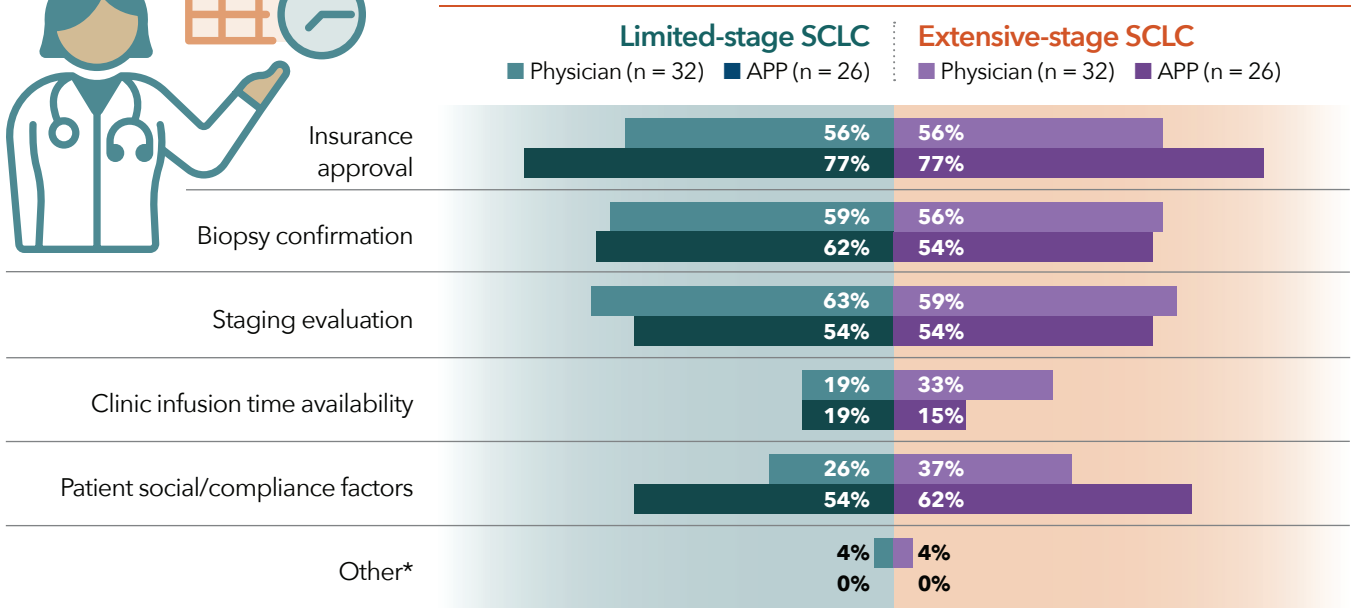


FIGURE 2. Provider-Reported Causes of Significant Treatment Delays for SCLC



*Patients often seek second opinions and this delays the start of treatment.

FIGURE 3. Provider-Reported Role of QOL in Treatment Decisions

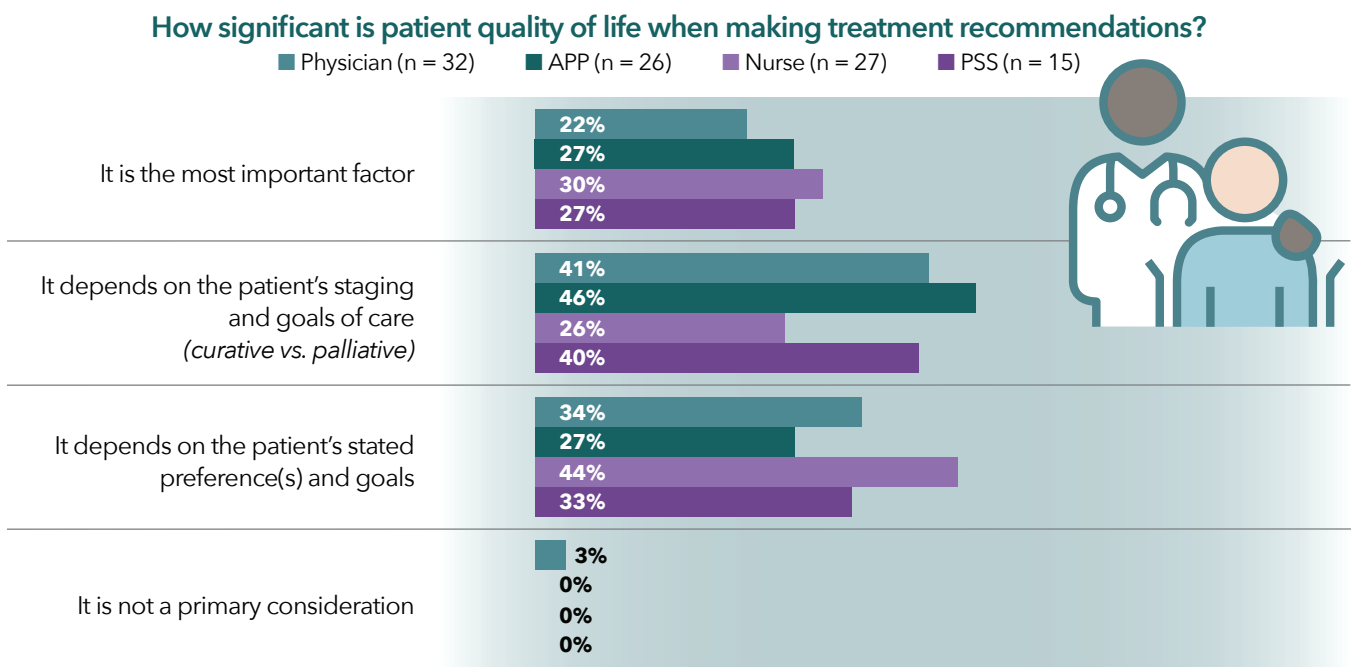
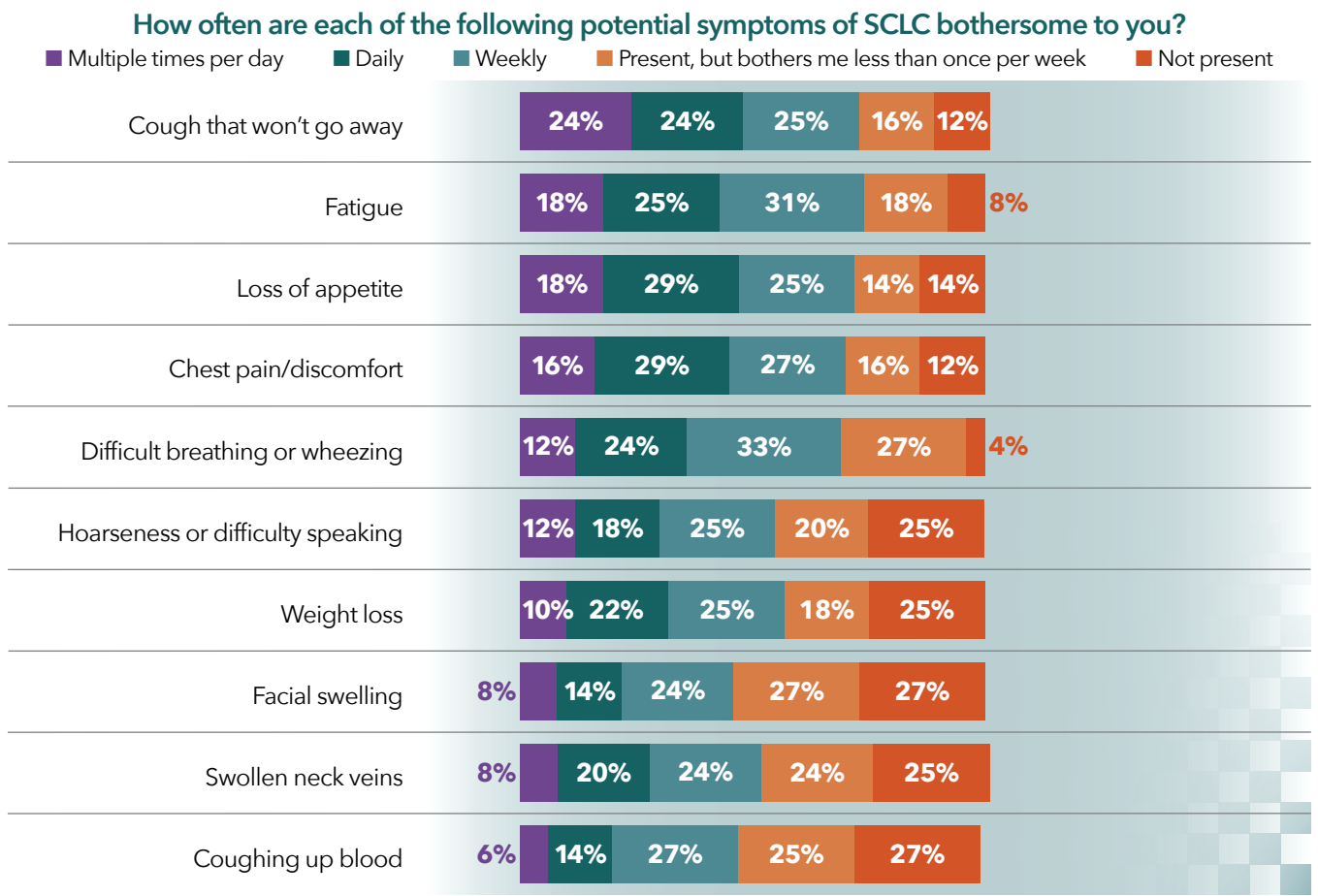


FIGURE 4. Patient-Reported Frequency of SCLC Symptoms



Other symptoms related to SCLC

Sleep issues/tired/weakness **8%**
 Back/spine pain/localized pain **6%**
 Trouble eating/weight loss **6%**
 Fever **3%**
 Blood issues/bleeding **3%**
 Inflammation/swelling **3%**

FIGURE 5. Treatment Patterns of Limited-Stage SCLC With Involved Nodes

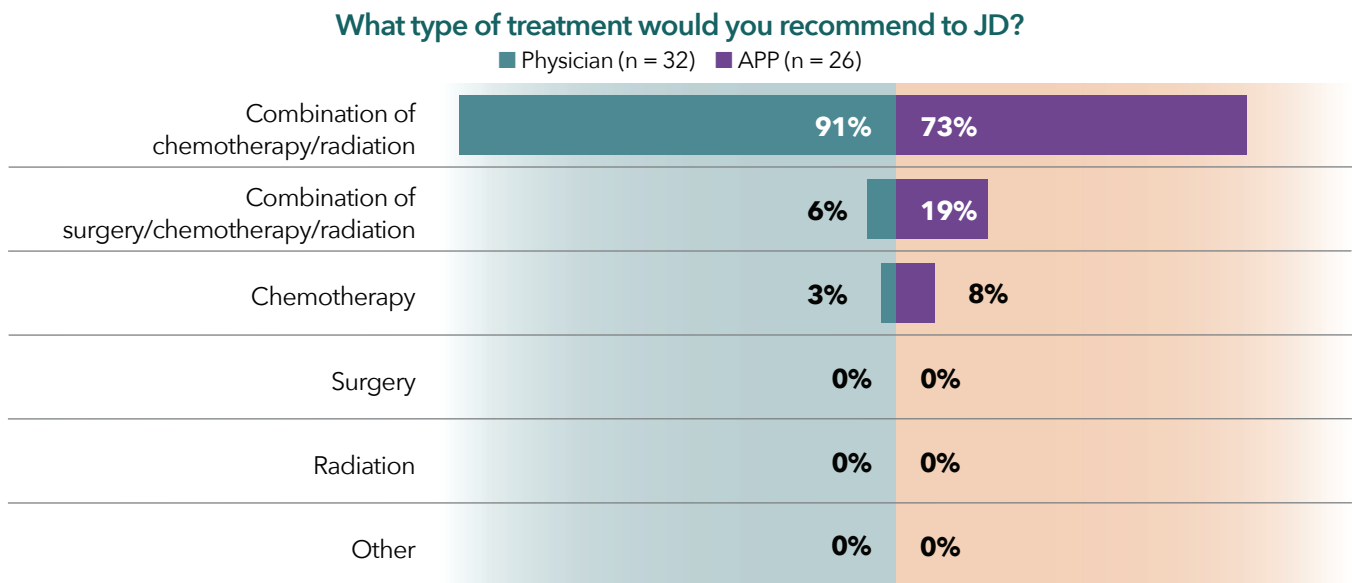


FIGURE 6. Clinical Trial Referral Rates for LS-SCLC

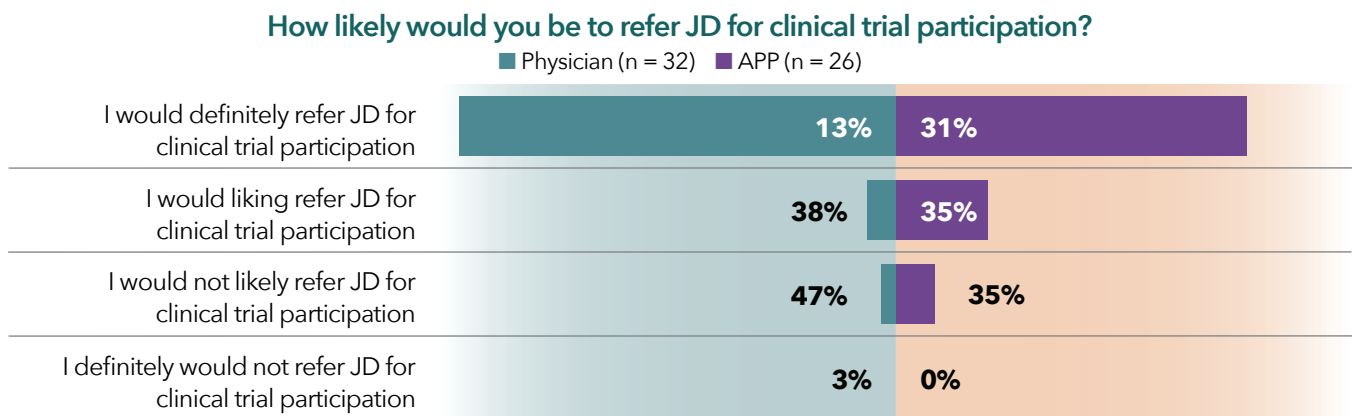


FIGURE 7. Provider Beliefs of Barriers to Clinical Trial Participation by Patients

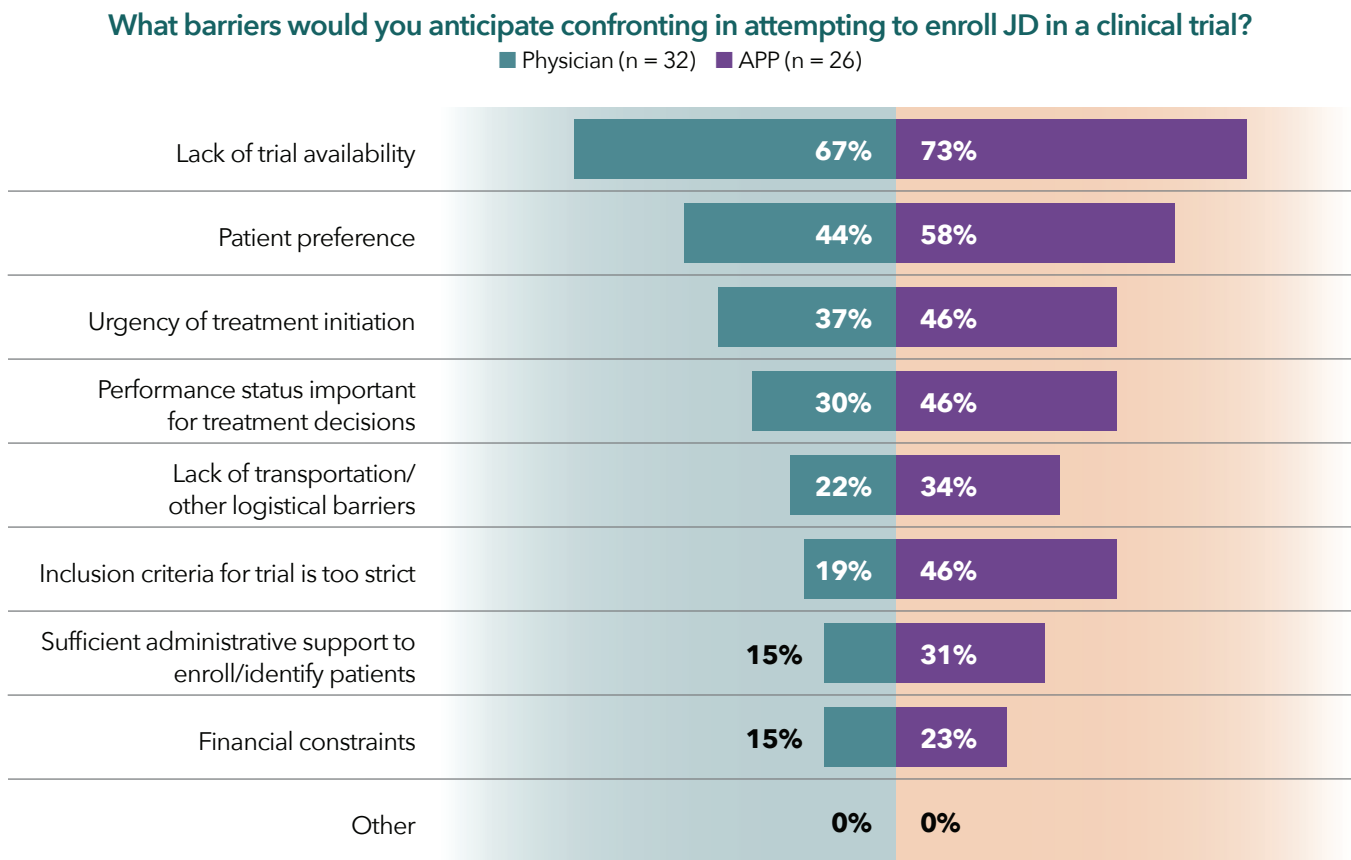


FIGURE 8. Patterns of Second-Line Treatment Initiation for ES-SCLC

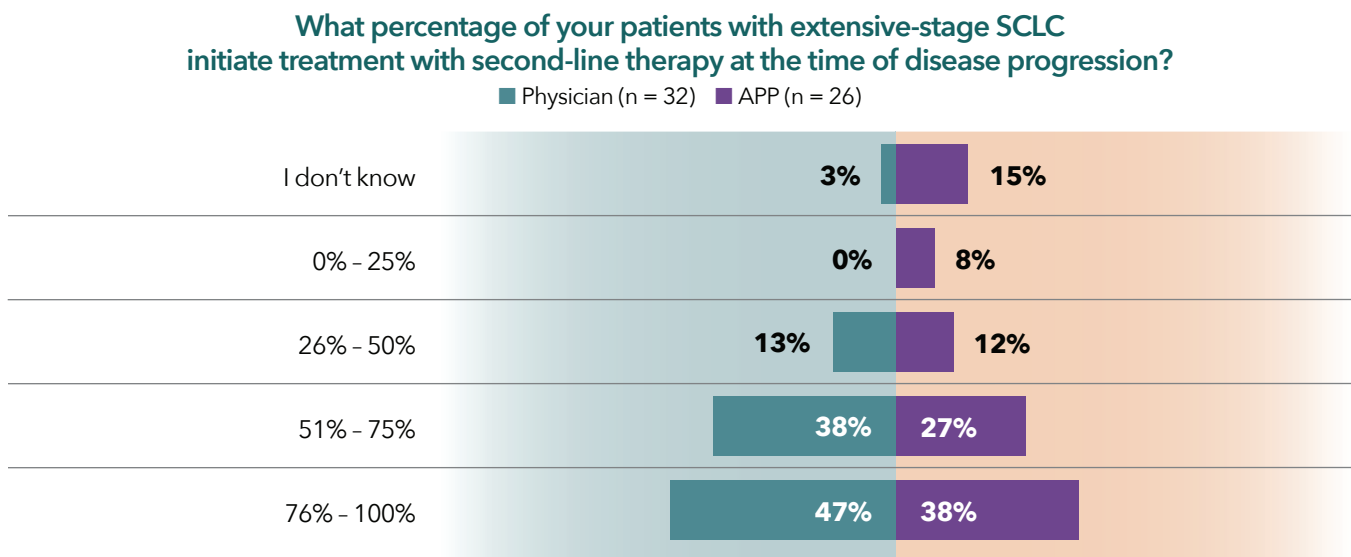
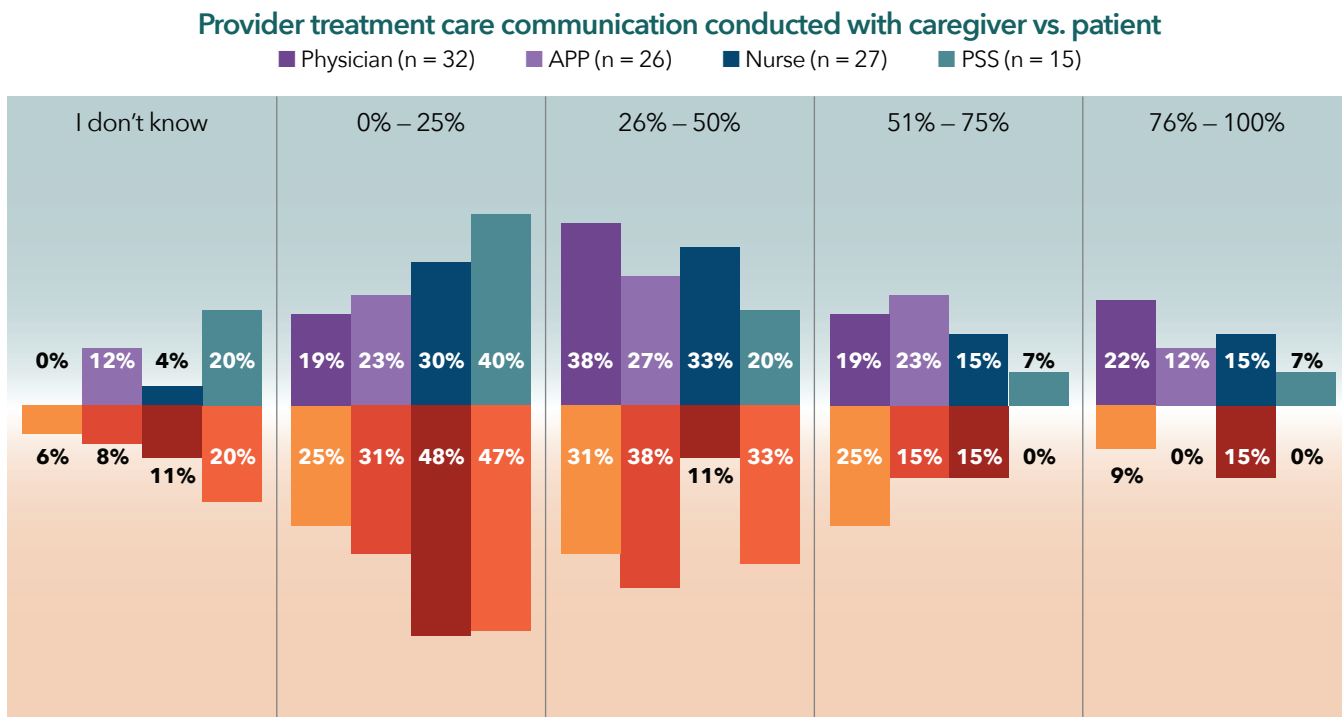


FIGURE 9. Provider Perception of the Role of Caregivers



Provider treatment care decision-making conducted with caregiver vs. patient

Legend: Physician (n = 32), APP (n = 26), Nurse (n = 27), PSS (n = 15)

FIGURE 10. Timing of Referral to Palliative or Supportive Oncology

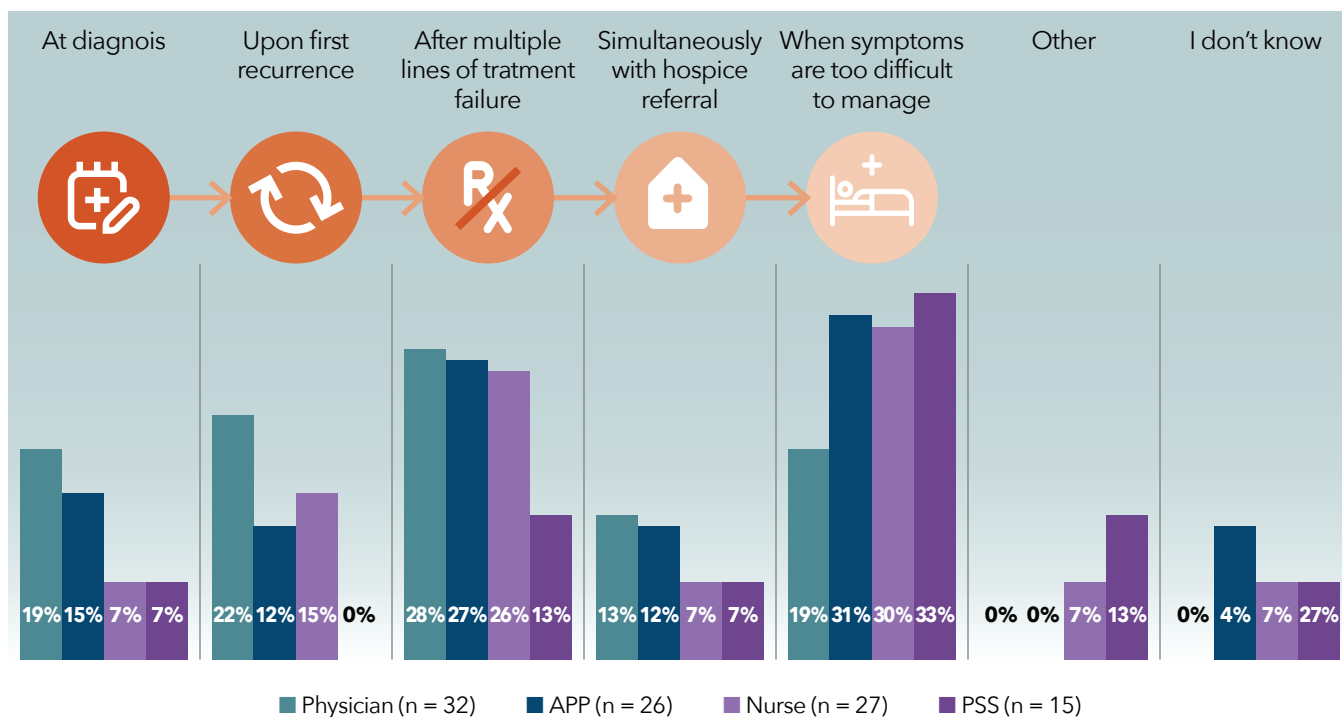


FIGURE 11. Proportion of Providers Who Would Offer Education to the Case Study Patient

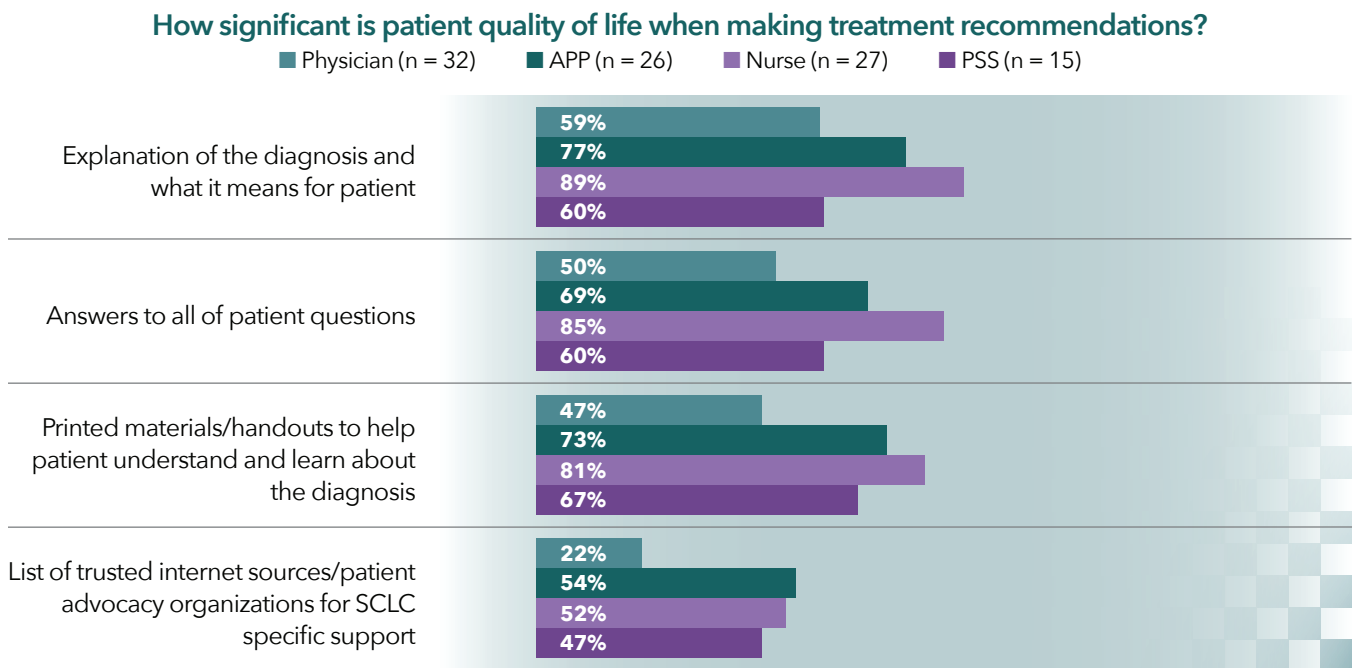
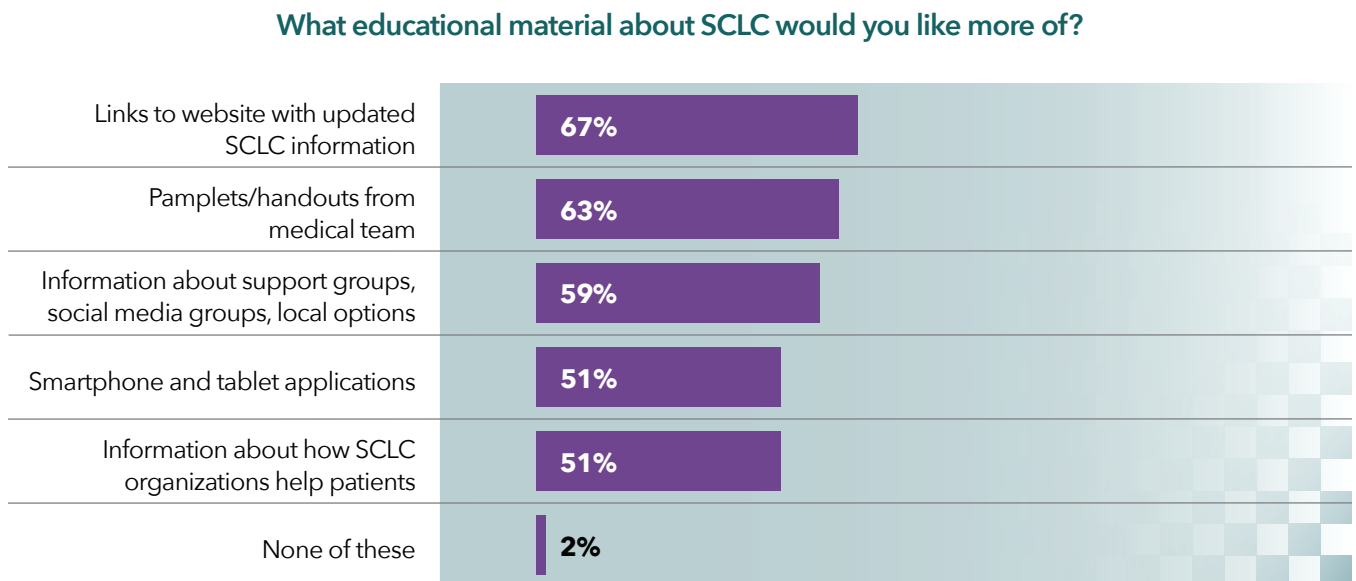


FIGURE 12. Patient-Requested Resources About SCLC



(continued from page 4)

Key findings from the patient survey include that caregivers are frequently involved in treatment and care planning, which highlights the importance of including caregivers in discussions at patient visits, and ensuring they are also provided with education, information, and trusted resources. In addition, patients want more information about where to find accurate and updated information about SCLC on the Web, via paper pamphlets or handouts, and/or smartphone applications. Patients are also interested in learning more about patient advocacy and pertinent support groups across their care journey.

Specific recommendations from both the patient and provider surveys include a need to increase the referral rates to, and use of, palliative care and supportive services, reduce barriers to clinical trial access, educate providers on the tools and resources for assessing quality of life and patient appropriateness for second- and subsequent-line therapies, and involve the patient's and caregiver's perspectives on care planning and treatment goals. Healthcare providers and care teams should consider increasing the promotion of these resources to patients as early as possible at and/or after diagnosis. In addition, more print resources should be developed and disseminated to multidisciplinary care teams to share with patients.

LIMITATIONS

There were some limitations of the surveys. For the provider survey, the sample size was 100, but this was subdivided, thereby decreasing the sample size for specific types of providers. In addition, the follow-up physician survey was developed after the initial survey and included a small sample size. For the patient survey, the sample size was small at 51, and LS-SCLC was over-represented relative to the epidemiologic proportion of patients diagnosed with LS-versus ES-SCLC. Therefore, the data discussed herein may not be fully representative of the larger provider and patient populations.

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- 7 Referenced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for **Small Cell Lung Cancer V.3.2023** ©National Comprehensive Cancer Network, Inc. 2022. All rights reserved. Accessed February 1, 2023. To view the most recent and complete version of the guideline, go online to [NCCN.org](https://www.nccn.org). NCCN makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way.
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Project supported by AstraZeneca and Jazz Pharmaceuticals
In partnership with LUNGEVITY Foundation



A publication from the ACCC education program, "Small Cell Lung CancerCare". Learn more at acc-cancer.org/scl-care or scan this QR code.

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