



# Supportive Oncology in Lung Cancer

Program Development  
for Patients and Care Partners

## IN BRIEF

This study provides a standardized methodology for supportive oncology patient and care partner program development that cancer programs and practices can tailor to guide future projects that serve other tumor site populations, including those with regional diversities and multiple locations. This study and its preliminary findings were accepted as an abstract by the American Society of Clinical Oncology for the association's 2022 annual meeting in Chicago, Illinois, and the proceedings are available online.<sup>1</sup>

**A**s the second most common cancer and most frequent cause of cancer-related death, lung cancer is a health care challenge.<sup>2-4</sup> Advances in treatment have led to only modest improvements in overall survival.<sup>5</sup> For those with advanced disease, symptom management is essential.<sup>6</sup> Patients with lung cancer experience a higher symptom burden than other patients with cancers<sup>7</sup>; these include dyspnea (difficulty and labored breathing), fatigue, impaired function, negative impacts on quality of life, and pain.<sup>8,9</sup> The array of these symptoms and needs underscore the vital role of supportive care to improve patient quality of life regardless of prognosis.<sup>10</sup>

Patients' unmet needs are greatest in those who are younger, have advanced disease, and have a lower quality of life.<sup>11</sup> Care partners' unmet needs include anxiety about the patient, disease-related information, and personal emotional support.<sup>12</sup> Both groups share common needs, including increased information,<sup>4,13</sup> health care professional interactions and services,<sup>13,14</sup> and strategies for daily living.<sup>4,13</sup> Resources and customized support services should address these unmet needs.<sup>4,11,14</sup> Tailored interventions must span lung cancer pathology, disease stage, and treatment types. Several initiatives have aimed to reduce patient pain and care partner anxiety,<sup>15</sup> modify risk factors for pulmonary complications,<sup>16</sup> and improve patient well-being.<sup>17</sup> Consistently, these individual interventions enhance health outcomes.

Across studies, educational programs have been designed and aligned with the patient population. Walsh et al<sup>18</sup> found that during the COVID-19 pandemic, online lung cancer support community participation enhanced patient capacity to process health information, receive psychological support, and find purpose in the community. During lung resection, educational programs reduced length of inpatient stay and postoperative complications<sup>17</sup> and lowered patient anxiety and pain scores.<sup>19</sup> In coping skills training and group education programs, patients show improved depression, quality of life, and self-efficacy, while care partners show lower anxiety and better

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self-efficacy.<sup>15</sup> The literature includes face-to-face education<sup>20,21</sup>; web-based<sup>22</sup> or telephonic programs<sup>15</sup>; and programs provided through 1 session,<sup>21</sup> multiple sessions over several weeks,<sup>16,23</sup> disseminated and printed educational materials,<sup>24</sup> or focus groups to garner information locally on how best to meet patients' needs.<sup>25</sup> To understand the comprehensive local needs of patients with lung cancer and their care partners, we studied a regional, multisite cancer program—Atrium Health, Levine Cancer Institute in Charlotte, North Carolina.

## Patients and Methods

A dedicated project team and qualitative needs assessment informed the development of a supportive care program for patients and their care partners. The project team and program development were supported by local stakeholders, including the Levine Cancer Institute's thoracic oncology section chief, Department of Supportive Oncology, and cancer committee executive leadership, as well as community and philanthropic partners (Figure 1, page 65).

The needs assessment was created in 2015 and was fielded within thoracic medical oncology at Levine Cancer Institute. The medical oncologists who focus on lung cancer provide care across more than 25 locations within the Atrium Health system and are supported by multidisciplinary teams. Within the health system, there are about 1000 new lung cancer diagnoses per year, mostly non-small cell lung cancer and about one-third are metastatic at diagnosis. The patient population for this study included 50% female, 18% Black, and 10% never smokers. The institutional review board at the cancer institute approved this study as a quality improvement project. Two qualitative methods were employed: (1) focus groups and (2) self-administered paper surveys. The focus groups shaped the surveys' design, and the data were analyzed to identify group overlaps.<sup>26</sup>

Focus group participants included health care professionals, a local lung cancer support group leader, patients, and care partners (n = 19), who were recruited based on purposeful sampling to garner critical viewpoints across groups.<sup>27</sup> Three, 90-minute focus groups were facilitated with a script based on prior patient, care partner,<sup>4,11-13,28</sup> and support program development research.<sup>15-19,29</sup> The project team reviewed and commented on the script prior to implementation to ensure it used common language. Focus group meetings took place virtually and were recorded (video and audio) and transcribed by Microsoft Teams—a digital communication and collaboration software tool with the capability of hosting group video calls and virtual meetings.<sup>30</sup> Focus group data were de-identified and analyzed thematically,<sup>31</sup> related to unmet needs, as well as format and content

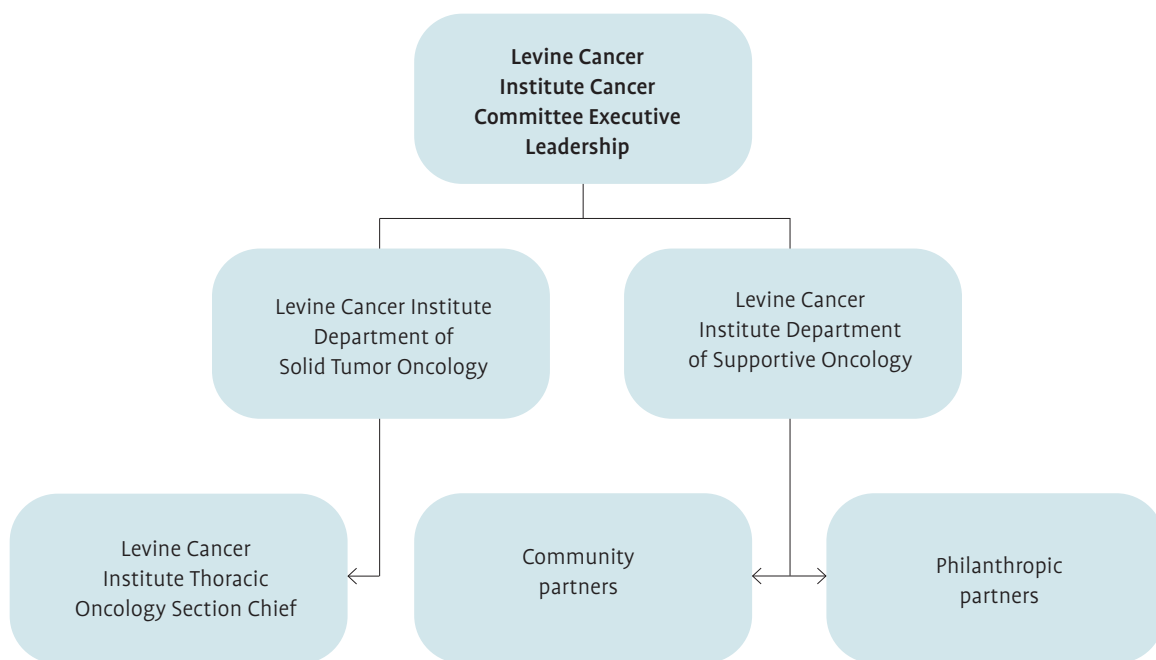
preferences. Thematic analysis required reading the transcribed data several times to identify patterns. These patterns were then coded into themes and codes, and further analysis was conducted to specify relationships across these themes.<sup>32</sup>

The self-administered paper surveys were based on qualitative, lung cancer, unmet needs research, support program research,<sup>18-21,24,25,33</sup> and our focus group analysis. Prior to finalization, the surveys were optimized for patient literacy. Patients and their care partners completed these surveys in the clinic waiting room. Participants (n = 44) were unique individuals from the focus groups. Survey data were managed using REDCap electronic data capture tools hosted at Atrium Health Wake Forest Baptist in Charlotte, North Carolina.<sup>34,35</sup> REDCap is a secure, web-based software platform designed to support data capture for research studies that has: (1) an intuitive interface for validated data capture; (2) audit trails for tracking data manipulation and export procedures; (3) automated export procedures for seamless data downloads to common statistical packages; and (4) procedures for data integration and interoperability with external sources. Survey data were extracted using REDCap report functions for descriptive analysis.<sup>36</sup>

## Results

Table 1, page 66, provides an overview of participants. Among the participants, 14 are female and 5 are male. Not all survey items were answered by all respondents. Available survey respondent demographics are in Table 2 (page 67); respondents (N = 39) are female

Figure 1. Project Team Stakeholders





(61%) and male (29%). Analysis of the focus groups identified 4 themes and 3 unique codes within each theme to provide analytic depth. Themes appear in order of frequency (n) of unique comments across these data (Table 3, page 67), including the following:

- Unmet needs (n = 25), with the unique codes of care of the care partner, loneliness, and onboarding burden
- Program structure (n = 24), with the unique codes of innovation, variability, and virtual
- Barriers to care (n = 20), with the unique codes of knowledge gaps, psychosocial barriers, and transportation
- Program content (n = 18), with the unique codes of content and services, educational, and financial

These codes were compared with survey data for overlap and were vital for informing the supportive care program. Representative quotes from participants are found in Table 4, page 68.

### Unmet Needs

Care of the care partner involves assistance for those who support patients with cancer. A participating care partner shared that supporting her loved one was an experience that made her feel like she had posttraumatic stress disorder. The second code, loneliness, encompasses focus group reflections on being alone in one’s cancer experience, summarized as, “You finally meet with your oncologist...then you go back out to the real world, and you’re the only one there.”

Finally, onboarding burden reflects the toll that a day of diagnosis-, treatment-, and financial-related discussions has on patients and their care partners. One patient shared the need to “shorten the onboarding experience” to alleviate the overwhelming quality of their first day in the clinic.

### Program Structure

Innovation includes ideas on how to best serve the local lung cancer population. This includes services like “the caregiver gets a 20-minute visit to the...respite room.” Variability speaks to a program with various service platforms and media for content dissemination. This was supported by a participating patient navigator, who said, “I think we definitely would need to have multiple modes of media.” Virtual encapsulated concerns regarding the need to maintain a virtual presence, which was shared by a participating nurse manager, stating that “We’ve...learned a really useful lesson through [the COVID-19 pandemic].”

### Barriers to Care

All participants spoke of knowledge gaps as barriers to acquiring information about their diagnosis, treatment, and finances. A participating nurse shared that she has “patients come in that...want every single resource that we have.” Transportation was also recognized as a barrier to attending treatment visits or symptom management services. A participating patient, who relies on her care partner for

**Table 1. Thoracic Oncology Focus Group Participants by Role and Gender**

FOCUS GROUP 1*	GENDER	FOCUS GROUP 2*	GENDER	FOCUS GROUP 3*	GENDER
Patient navigator 1	Female	Dietitian/nutritionist 1	Female	Nurse 1	Female
Patient navigator 2	Female	Occupational therapist 1	Female	Nurse manager 1	Female
Patient navigator 3	Female	Dietitian/nutritionist 2	Female	Patient 2	Female
Local lung cancer support group leader	Female			Care partner 1*	Male
Patient 1**	Male			Volunteer services coordinator 1	Female
				Physical therapist 1	Female
				Nurse 1	Male
				Acupuncturist 1	Male
				Patient 3	Female
				Care partner 2	Female
				Care partner 3	Male

\*Focus group roles replaced names to maintain anonymity.

\*\*Patients and care partners are not necessarily associated with one another.

**Table 2. Thoracic Oncology Self-administered Paper Surveys Respondent Demographics**

VARIABLE	RESPONSE FREQUENCIES (N, %)
Gender (n = 39)	Female (24, 61%); Male (15, 39%)
Age groups (n = 40)	40-49 years (2, 5%) 50-59 years (6, 15%) 60-69 years (13, 33%) 70-79 years (19, 47%)
Hispanic, Latino, or Spanish (n = 40)	Yes (1, 2%); No (39, 98%)
Race (n = 39)	White or Caucasian (26, 67%) Black or African American (13, 33%)
Community (n = 32)	Rural (9, 28%) Urban (10, 31%) Suburban (13, 41%)
Medical insurance (n = 39)	Yes (38, 97%); No (1, 3%)
Care partner employed (n = 19)	Yes (5, 26%); No (14, 74%)
Highest education level (n = 37)	Less than high school diploma (7, 19%) High school diploma (8, 22%) Some college, no degree (10, 27%) Associate degree (5, 14%) Bachelor's degree (5, 13%) Master's degree (2, 5%)

transportation, shared that “it [is] just hard...there’s days that he doesn’t drive, and there’s days that he does.” Psychosocial-related concerns include patients’ fears and worries that are barriers to care.

**Program Content**

The content and services code describes the activities that combine the required content into service offerings. For example, a participating nurse manager shared that “integrative [oncology] provides awesome support for [fatigue] and...couple that [with] physical therapy.” Educational barriers were described by a participating patient as wanting “to know more about...[what] they were looking at...the genetic stuff.” While financial concerns are described as “really hard, especially if someone [doesn’t] qualify for charity,” by a participating leader from a local lung cancer support group, “they [patients] also are broke.”

Analysis of focus group and survey data revealed strong overlap between participants’ responses in knowledge gaps, psychosocial barriers, content and services, financial and educational content, variability, and virtual. Most focus group and survey participants agreed on knowledge gaps and psychosocial-related concerns as being barriers to relief of their unmet needs. The majority across both groups agreed with content and services and the importance of educational and financial issues. Modes of variability were specified with printed and patient-portal digital materials, with a moderate preference for virtual meetings among participants. Discordance across both data sets was found for loneliness and transportation, while care for the care partner, onboarding burden, and innovation were neutral or irrelevant.

*(Continued on page 69)*

**Table 3. Comparisons Across Focus Group and Self-administered Paper Survey Data**

THEME (FREQUENCY = N)	FOCUS GROUP CODE*	SURVEY RESPONSES (N, %)
Unmet needs (n = 25)	Care for the care partner Loneliness Onboarding burden	Neutral (6, 38%) Agree (13, 36%) N/A
Program structure (n = 24)	Innovation Variability Virtual	N/A Print (9, 75%) & Digital (5, 42%) Prefer (6, 38%)
Barriers to care (n = 20)	Knowledge gaps Psychosocial Transportation	Disagree (23, 68%) Agree (34, 59%) Agree (33, 67%)
Program content (n = 18)	Content and services Educational Financial	Agree (23, 61%) Agree (18, 90%) Agree (34, 56%)

\*Codes capture patterns within a theme.

**Table 4. Representative Quotes for Each Theme/Code From Focus Group Data**

NEEDS	
<b>Care for the care partner</b>	“When you’ve been swimming in those waters...I really felt like I had PTSD.” (Care partner 1*)
	“They must be their own advocates, and that, I guess, that’s not really fair.” (Nutritionist 2)
<b>Loneliness</b>	“...finally meet with your oncologist...you go back out to the real world...you’re the only one there.” (Patient 1*)
	“It’s almost like a sense of relief for them that...they found their people.” (Local lung cancer support group leader)
<b>Onboarding burden</b>	“We give a lot of information at consult...so overwhelming.” (Patient navigator 1)
	“Shortening the onboarding experience.” (Patient 1)
PROGRAM STRUCTURE	
<b>Innovation</b>	“You could do more...caregiver gets a 20-minute visit to the...respite room they have now.” (Occupational therapist 1)
	“...someone can, you know, get transportation for a chemo[therapy] treatment or something like that.” (Care partner 1)
<b>Variability</b>	“I think we definitely would need to have multiple modes of media, you know, for different people...” (Patient navigator 1)
	“Like maybe an orientation...introduce the mentorship platform [and] some partner groups.” (Local lung cancer support group leader)
<b>Virtual</b>	“I’ll still keep some things virtual ‘cause we’ve learned a really useful lesson through [COVID-19]...” (Nurse manager 1)
	“Virtual. I will say that.” (Patient 1)
BARRIERS	
<b>Knowledge gaps</b>	“I have patients [wanting] every resource...others that just finished chemotherapy but [are] now interested in this thing.” (Nurse 1)
	“[Patients with] lung cancer...[are] different; some that ‘wanna know everything...and some do not.” (Patient 1)
<b>Psychosocial</b>	“There’s a pool of [patients with] lung cancer...who are afraid to leave the house.” (Patient 1)
	“It’s really hard to get people to find the energy or motivation to come to stuff.” (Nutritionist 1)
<b>Transportation</b>	“Patients say they don’t want to ask for one more ride...they’re not gonna come in.” (Occupation therapist 1)
	“It [is] just hard for [the care partner]...there’s days that he doesn’t drive and [days] that he does.” (Patient 3)
PROGRAM CONTENT	
<b>Content and services</b>	“Fatigue is going to be prevalent...integrative [services] provides support and couple that [with] physical therapy.” (Nurse manager 1)
<b>Financial</b>	“Unfortunately, lung cancer doesn’t mean cancer...someone [doesn’t] qualify for charity, but they also are broke.” (Local lung cancer support group leader)
	“People are making decisions and leaving money on the table.” (Patient 1)
<b>Educational</b>	“API or BRAC, you know, give me a good word for that all the genetic stuff.” (Patient 2)
	“Patients that are years into treatment...I don’t know if it’ll ever get through.” (Patient navigator 1)

(Continued from page 67)

### Program Development

Following the needs assessment, subject matter experts with interest and the capacity to participate in the working group began a project feasibility phase. This entailed identifying relevant and existing service lines, which comprise individual or group activity programs that support end users' goals. At the time of review, there were no active care partner support services offered by thoracic or supportive oncology at Levine Cancer Institute. Next, in the feasibility phase, programs that required engagement outside of the cancer institute's Department of Supportive Oncology were considered. These external programs include the departments and/or clinical sections that coordinate thematic activities and ongoing evaluation of outcomes, as well as objectives and goals that align with the needs of patients and their care partners.

This feasibility phase recognized gaps that needed to be resolved by creating new or reviving older services and programs. Table 5, below, outlines the relationships between qualitative themes and codes and the associated services or programs that emerged from these findings. For example, the barriers to care theme and related knowledge gaps code were associated with treatment advances delivered through Facebook Live, tobacco cessation through supportive oncology services, and other relevant specialty clinics. The final supportive care program included services like cancer rehabilitation, financial counseling, genetics counseling, nurse navigation, oncology nutrition, and tobacco cessation, as well as programs like integrative oncology, a patient resource center, palliative medicine, psycho-oncology, senior oncology, and survivorship clinics.

Before the services and programs with new content launched, a series of mechanisms were established to support promotion and dissemination. A one-page paper flyer was created that included health-literate descriptions of specialty clinics and a quick response (QR) code—an innovative use of a digital barcode that can be easily scanned with a cell phone and that assists in information accessibility.<sup>37</sup> A QR code responds to the need for virtual program access and the variable need for a “digital” program structure (Table 5). Users can access specific content from our Supportive Care Lung Cancer Program online and trusted community resources about loneliness using QR technology. Specialty clinics include integrative oncology, a lymphedema clinic, neuropsychology, palliative medicine, psycho-oncology, and senior oncology. The QR code technology enhanced awareness for our new programs and services.

Educational videos were posted online within a dedicated playlist on the Levine Cancer Institute supportive oncology YouTube channel. Videos are always accessible and address the variability and virtual codes identified in this study. Our videos also address the barriers to care that were identified in the knowledge gaps code. One innovative use of YouTube was the creation of the Kazoo Blews program. In these videos, a Levine Cancer Institute music therapist introduces the pursed lip breathing technique for better inhaling and exhaling using a kazoo. This multi-video playlist shares why and how one should use and clean the kazoo and provides the opportunity to play alongside Levine Cancer Institute's music therapist from the comfort of their home. Kazoos are now available in the thoracic oncology clinic, along with the QR code for access to the playlist.

As patients and care partners live across rural and urban settings, Facebook Live allows subject matter outreach to patients and care

**Table 5. Example of Supportive Oncology Programs and Services Identified and Developed to Address Unmet Needs and Barriers**

THEME	FOCUS GROUP CODE*	PROGRAMS OR SERVICES
<b>Unmet needs</b>	Care for the care partner Loneliness Onboarding burden	Transferring loved one from and in and out of a car/chair (YouTube videos) Community resources One-page paper flyer with program contact and referral information, navigating health care (Facebook Live)
<b>Program structure</b>	Innovation Variability Virtual	Quick response (QR) code to access lung specific programming YouTube videos, 1-pager with program specifics Facebook Live events
<b>Barriers to care</b>	Knowledge gaps Psychosocial barriers Transportation	Treatment advances (Facebook Live), tobacco cessation (LCI DSO services), specialty clinics Lower anxiety (Facebook Live) Resource center, navigation, and social work
<b>Program content</b>	Content and services Educational  Financial	Specialty clinics, how to beat fatigue, pain management, and sleep Financial counseling (LCI DSO services) Genetics counseling (LCI DSO services), navigating health care (Facebook Live) (Facebook Live)

LCI DSO, Levine Cancer Institute Department of Supportive Oncology  
\*Codes capture patterns within a theme.

partners with transportation barriers (Table 3). Topics delivered by subject experts include exercise during treatment, fatigue tips, and how to lower anxiety and pain. This platform provides education about lung cancer treatment advances and health care navigation. This content addressed multiple codes identified in this study, including psychosocial, knowledge gaps, educational, and virtual. Patients and care partners can engage with our subject matter experts virtually in a well-known and easily accessible platform free of charge.

Further, the project team will oversee the new supportive care program and monitor the unmet needs and barriers of patients with lung cancer and their care partners. This includes trends in information accessed by patients and their care partners, as well as referrals from the thoracic oncology clinic to the Department of Supportive Oncology. The team will continue to assess face-to-face and online class attendance, as well as these services and programs.

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### A commitment to using common language across materials was an important step that strengthened participant engagement.

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#### Discussion

In this study, we conducted 3 focus groups and administered paper-based surveys to identify unmet needs and barriers to care for patients with lung cancer and their care partners. Based on these data, we developed a supportive care program at Levine Cancer Institute to address identified issues. Focus group analysis identified 4 themes, and each theme was analyzed further into 3 unique codes. Among survey responses, strong overlap existed in 6 areas:

- Knowledge gaps
- Psychosocial barriers
- Content and services
- Educational and financial content
- Variability
- Virtual

Participating patient, care partner, and health care professional voices provided rich perspectives to develop a robust supportive care program. Overall, the needs assessment followed steps that articulated the study's purpose, identified participants to provide insights into local needs, established the study's resource needs, and determined how to implement findings and improvements. Throughout this process, we reflected on the strengths and weaknesses of this project.


Several aspects of this study worked well with our supportive care program development. A strength of this project was the enthusiastic project team, working across departments, and patient group that supported the study's methods. For example, the project included an

engaged physician leader who supported health care professional participation and that subject matter experts be ready to establish specialized program content. A commitment to using common language across materials was an important step that strengthened participant engagement. Outside thoracic medical oncology at Levine Cancer Institute, several individuals provided vital patient-facing material, and local community and philanthropic partners helped bring these materials to our target population. To our knowledge, this is the first report on QR code usage in supportive oncology, which is an innovation in this patient population.

The complementary needs assessment methods provided in-depth, local knowledge to support unmet needs and address barriers to care. The discordance between focus group and survey data might appear problematic, however, this became a strength. For example, focus group data were highly significant and articulate about the theme of caring for the care partner. However, survey data suggested no significance. The importance of the focus group data necessitated educational programming content. This decision is also supported by previous research findings that recommend health care partners receive resources, information, and support to maintain good health and sustain their role in the patients' cancer journey.<sup>38-40</sup> Levine Cancer Institute's supportive oncology YouTube channel provides this content, for example, how caregivers can safely and efficiently transfer a patient in and out of the car or a chair.

Alongside the strengths of this project, we also recognize weaknesses. The project team did not take the time to capture baseline data before program implementation, which would be helpful to assess program outcomes. Additionally, only 1 researcher collected and analyzed data, which limits the rigor associated with intercoder reliability. However, our study was not intended to produce generalizable data. We did not focus on cancer- or population-specific demographics as end points; study findings may not adequately represent the care continuum or subsets of lung cancer.

Lung cancer is both common and lethal; yet organized support trails other more common and less-stigmatized malignancies. The creation of a resource platform addresses unmet and evolving needs, while minimizing barriers to accessing care.

Still, the study provides a standardized methodology for supportive oncology patient and care partner program development that cancer programs and practices can tailor to guide future projects that serve other tumor site populations, including those with regional diversities and multiple locations. 

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