Comprehensive Quality Care for Patients with Small Cell Lung Cancer

Effective Practice: Comprehensive Support Program

Insights from Levine Cancer Institute, Charlotte, NC

"Historically there has been a lot of blame when a person receives a lung cancer diagnosis—blame from others, but also people with lung cancer often blame themselves. In my experience, people living with lung cancer commonly feel their needs are not recognized. I am proud of the fact we started a support program for patients with lung cancer to show we do care, and we can offer tailored services based on the patient's type of lung cancer."





The Charge

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Levine Cancer Institute serves patients in North Carolina and South Carolina. As part of the Commission on Cancer's annual accreditation initiative, Levine was tasked with designing and implementing a cancer support program. The Commission did not specify a tumor type, but the standing-up of a non-funded program was to be completed within one-year.

Based on distress screening data, Levine's Cancer Committee identified an opportunity to improve support for patients diagnosed with lung cancer. Levine sees a wide range of people impacted by lung cancer. Each year, the health system diagnoses 900 new cases of lung cancer, with approximately 150 cases representing small cell lung cancer.

In addition, Levine sits within the tobacco belt, which contributes to the incidence of small cell lung cancer cases. However, there are also cases of lung cancer amongst people who have never smoked. The Cancer Committee coalesced around a lung cancer support program. A thoracic medical oncologist championed the initiative and assembled a passionate and committed multidisciplinary team including a physical and occupational therapist, music therapist, psychologist, patient resource manager, nurse navigators, nutritionist, social worker, research scientist, and program coordinators. At the outset, it was important to the team that whatever program they designed met the needs of the entire patient population.

Needs Assessment

To have a full picture of the needs of patients and caregivers, the team started with a needs assessment.



STEP 1

Work with a member of the Levine research team to design a series of focus groups



STEP 2

Conduct focus groups with patients, caregivers, and multidisciplinary care staff to identify unmet needs



Develop and disseminate a patient survey at multiple clinics

Synthesi

Synthesize key unmet needs of patients, caregivers, and providers based on results

Focus group conversations were framed around patients' needs. The team found that what the providers felt patients wanted, what the patients wanted, and what the caregivers felt the patients wanted, were all very different things.

The team then created a crosswalk of available services by department, but also recognized the availability of external organizations in their region that support people with lung cancer, which could be further leveraged. The team invited input from these external organizations to ensure the program they developed was complementary and not duplicative.

Program Development

A common theme that emerged was patients wanted a variety of information across multiple platforms. Topic areas of interest across lung cancer types were:

- Nutrition
- Safety (e.g., how a family member or caregiver can safely transfer a person living with lung cancer in and out of the car)
- Medication management

In addition, the team used the crosswalk to focus on gaps and/ or opportunities to enhance services, such as:

- Creation of the Kazoos Blews Program, a joyful music therapy program to also exercise the lungs
- Review and revision of materials using health literacy best practices
- Creation of publicly available digital and mobile friendly content (eg, YouTube videos, Facebook Live) to complement existing in-person services
- Creation of a QR code, which takes patients to all publicly available content. Digital content is also available on tablets and televisions in the infusion center in case internet access is limited outside of the clinic
- Creation of a print piece that summarizes all resources with direct contact phone numbers and e-mail addresses

Specific Needs of Patients with Small Cell Lung Cancer

As the team developed the program, they were cognizant of specific needs of patients with small cell lung cancer. The team ensured incorporation of their robust smoking cessation program into services offered. The team also prioritized connecting patients with small cell lung cancer to supportive oncology services at diagnosis, as well as offering emergency appointments to address acute pain management.

Next Steps

Levine Cancer Institute now has a solid foundation in place to provide ongoing support to people impacted by lung cancer. Yet, there remains commitment from the team to continue to innovate and build out additional services to meet patients' needs.

About the Kazoos Blews Program

The team identified the need for additional joyful music therapy for patients living with lung cancer. The music therapist recommended using kazoos as an accessible, low-cost, and dishwasher safe instrument.

The kazoo fits in your pocket, it is a fun to exercise your lung muscles (instead of a spirometer) and can be a group event in or outside of the clinic.

The team assembled and distributed hundreds of kits which included a QR code to the lung cancer support program videos.



The team also recently put together a printed list with instructions and suggested songs to ensure all people have access regardless of internet connectivity.



A publication from the ACCC education program, "Comprehensive Quality Care for Patients with Small Cell Lung Cancer." Learn more at accc-cancer.org/comprehensive-sclc-care.

The Association of Community Cancer Centers (ACCC) provides education and advocacy for the cancer care community. For more information, visit **accc-cancer.org**.

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