



# An Exploration of Supportive Care in Lung Cancer Survivorship

LUNG CANCER ALLIANCE

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## INTRODUCTION

1 in 15 people in the US will be diagnosed with lung cancer in their lifetime. Oncology clinical guidelines increasingly recommend an expansion of multidisciplinary care to include supportive and survivorship care. Despite current recommendations and research showing the need for such beneficial services, lung cancer patients may not have access to this type of care.

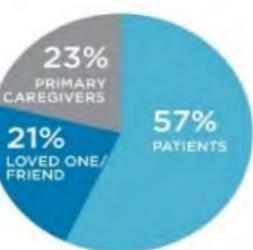
Our study goal was to assess supportive care needs and the accessibility of treatment and care planning from the perspectives of lung cancer patients and their caregivers.

## METHODOLOGY

A "Lung Cancer Community Needs Assessment" anonymous online survey was developed by Lung Cancer Alliance (LCA) and electronically distributed to lung cancer patients and caregivers from 11/9/2015 to 2/8/2016. The survey was promoted electronically through social media (Twitter and Facebook) and electronic newsletters. The survey URL was also posted twice to the Inspire online patient support community. In addition, 15 long-term survivors known to be without internet access were called by a LCA staff member and 10 of them completed the survey by phone.

The survey assessed the patient's physical and emotional side-effects experienced during active treatment and throughout survivorship.

- 820 people responded, including 471 patients/survivors and 349 caregivers, 181 of whom were the primary caregiver.
- The overall completion rate was 72.6%.



Demographic questions were optional and the number of respondents is indicated. Demographic information was collected to determine if patterns of care correlated with geographical or socioeconomic factors.

## DEMOGRAPHICS

Demographic data reflects the 471 survey respondents who identified as patients.

<b>Sex</b>	(n=407)	
Male	68	16.7%
Female	339	83.3%
<b>Race</b>	(n=365)	
White	342	93.7%
Black/African American	7	1.9%
American Indian/Alaskan Native	2	0.5%
Japanese	1	0.3%
Chinese	8	2.2%
Other Asian	2	0.5%
Other	3	0.8%
<b>Ethnicity</b>	(n=302)	
Hispanic/Latino	6	2.0%
Not Hispanic or Latino	296	98.0%
<b>Residential Setting</b>	(n=411)	
Rural	96	23.36%
Suburban	235	57.18%
Urban	80	19.46%
<b>Household Income</b>	(n=363)	
Less than \$20,000	27	7.4%
\$20,000 - \$39,999	41	11.3%
\$40,000 - \$59,999	74	20.4%
\$60,000 - \$79,999	53	14.6%
\$80,000 - \$99,999	50	13.8%
\$100,000 and over	118	32.5%

Caregiver-reported patient demographics represented a different population:

- 51% male, 48% female
- Majority 40-60 at diagnosis
- 91% white, 96% not Hispanic
- 34% never smoker, 41% former, 22% current smoker
- Cancers diagnosed later stage
- NSCLC: 68% Stage IV, only 10% Stage III
- SCLC: 64% Extensive, 27% Limited
- 55% said the patient they cared for is no longer alive

## INDIVIDUAL RESPONSES

"Please describe any needs that you had that you feel were not met when you were going through treatment (n =221 patients and caregivers who responded to open-ended question)."

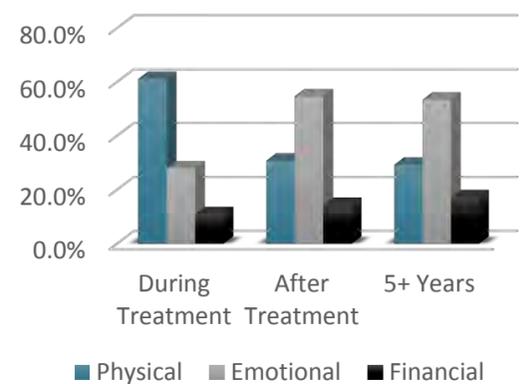


## RESULTS

95% of lung cancer patients reported having at least one side effect **during active treatment**.

- Physical side effects were rated most problematic.
- Only 26.9% of active patients discussed palliative care
- Only 20.13% received palliative care
- Fatigue, anxiety, and shortness of breath were the most prevalent problems at all time periods.

Emotional side effects were rated most problematic by patients and caregivers **during survivorship and beyond 5 years**.



Less than 50% of patients had a discussion about their values and care goals with their treatment team **before starting treatment**.

- Only 38% reported having discussed their **current values** and goals with their care team.
- Many of the optional write in comments noted "I was never asked" or "it never came up".

## LIMITATIONS

- The Needs Assessment was internet-based and therefore does not represent the entirety of the lung cancer community. There was also poor ethnic and racial diversity in the survey population.
- The majority of respondents were women

## CONCLUSIONS

The majority of lung cancer patients and caregivers perceived a lack of attention to supportive care during active treatment and throughout survivorship. Respondents were technology enabled and health literate indicating that these problems could be more widespread in rural, lower socioeconomic areas where lung cancer is common

Future research must address these problems in health care delivery to positively impact the survivorship of lung cancer patients and their families.