

**Burden of financial toxicity of lung cancer
treatment:**
*Understanding the patient and caregiver
perspective*

ACKNOWLEDGMENTS

LUNgevity Foundation and CancerCare are deeply indebted to our patient and caregiver community for taking the time to share their perspectives and making this research possible.

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About LUNgevity Foundation

About CancerCare

CancerCare® is the leading national organization dedicated to providing free, professional support services including **counseling**, **support groups**, **educational workshops**, **publications** and **financial assistance** to anyone affected by cancer. All CancerCare services are provided by oncology social workers and world-leading cancer experts.

EXECUTIVE SUMMARY

Background:

Growing patient financial responsibility in healthcare has introduced a new concept into the healthcare lexicon: **financial toxicity**. The term, coined by S. Yousuf Zafar, MD, and Amy Abernethy, MD, from the Duke Cancer Institute in Durham, North Carolina, describes an "adverse event" increasingly experienced by patients with cancer. Despite the growing attention to cancer costs by insurers and policy makers and the need for that aspect of care to be addressed in the clinical setting, several studies have found that this topic is not adequately addressed by oncologists and other clinicians. The rising costs of cancer care are most often discussed at the level of health policy with an eye toward societal financial burden, but are rarely from the perspective of the patient (or their caregiver).

Methods:

In order to understand how the changing treatment landscape of lung cancer is impacting the financial health of lung cancer patients and caregivers, LUNgevity Foundation and CancerCare decided to undertake the task of cataloging financial toxicities associated with a lung cancer diagnosis among patients and caregivers served by the two organizations. Using a semi-structured survey, the perspectives of 257 patients (190 from LUNgevity and 67 from CancerCare) and 45 caregivers (37 from LUNgevity and 8 from CancerCare) were gathered.

Results:

Of the 302 participants surveyed,

- Fifty-two percent of the respondents reported high levels of stress at the beginning of or during their cancer treatment
- One-in-three respondents reported that their cancer treatment had caused them financial hardship (a lot or extreme amount)

When the impact of a lung cancer diagnosis on overall psychosocial stress and financial hardship between respondents of the two groups (LUNgevity Foundation and CancerCare) were compared,

- Sixty percent of CancerCare respondents experienced a lot or an extreme amount of financial hardship, but only 29% of respondents from LUNgevity Foundation did (LUNgevity participants were 3.4 times less likely to report an extreme amount of financial hardship, as compared to CancerCare respondents)
- Fifty percent of respondents from CancerCare reported that they either found it difficult to manage or unable to manage the financial hardship associated with a lung cancer diagnosis, but only 24% of LUNgevity respondents did (LUNgevity participants were 3.5 times less likely to report an extreme amount of financial hardship that they were unable to manage, as compared to CancerCare respondents)
- The differences in the burden of financial toxicity between the two groups can be attributed in part to demographic factors, such as socio-economic status, levels of education, and racial and ethnic composition, factors that have been previously reported to predict access to care and health-seeking behavior.

Conclusions:

Our study confirms that lung cancer patients and caregivers experience financial toxicity because of increases in their out-of-pocket costs to manage their cancer care. Furthermore, social determinants of health (such as race and ethnicity, education, and income) intersect to compound the effects of increasing healthcare costs associated with a lung cancer diagnosis. Indeed, respondents from CancerCare expressed their financial concerns in context of financial costs associated with nutritional needs, their transportation costs, outstanding and unresolved hospital bills and co-pays due to confusion managing insurance coverage needs. Our study illustrates the need for effective social support programs and patient navigator programs, which can decrease patients' cost of care not by changing treatment but by referring them to financial assistance in a timely fashion. In addition, our study reinforces the importance of taking into account social determinants of health when conceptualizing assistance programs for cancer patients.

INTRODUCTION

Lung cancer continues to be the number-one cancer killer in the United States and worldwide.^{1,2} It is often discovered at later stages of the disease when extraordinarily difficult decisions must be made rapidly. These decisions are dependent, or should be, on the patient’s particular preferences. With a high overall mortality rate, 19% alive at the 5-year mark, the focus has been on new diagnostics and new therapies to save lives.² In the last few years, science has progressed at an unprecedented rate as new categories of therapies become available including immunotherapies and targeted therapies with companion diagnostics, while the application of existing therapies is being expanded. Despite this progress, access to these live-saving therapies continues to be an issue due to the financial toxicity associated with lung cancer treatment.

Coined by Drs. Amy Abernethy and S. Yousuf Zafar³, the American Cancer Society now uses the terms “financial toxicity” and “financial distress” to describe how out-of-pocket costs can cause financial problems for a patient.⁴ Out-of-pocket expenses include expenses throughout the lung cancer journey, from screening and diagnosis to treatment and palliative care. Based on data collected from 2011-2014, a recent report from Milliman suggests that lung cancer diagnosis and treatment is prohibitively expensive for the patient, as compared to breast and colon cancer.⁵

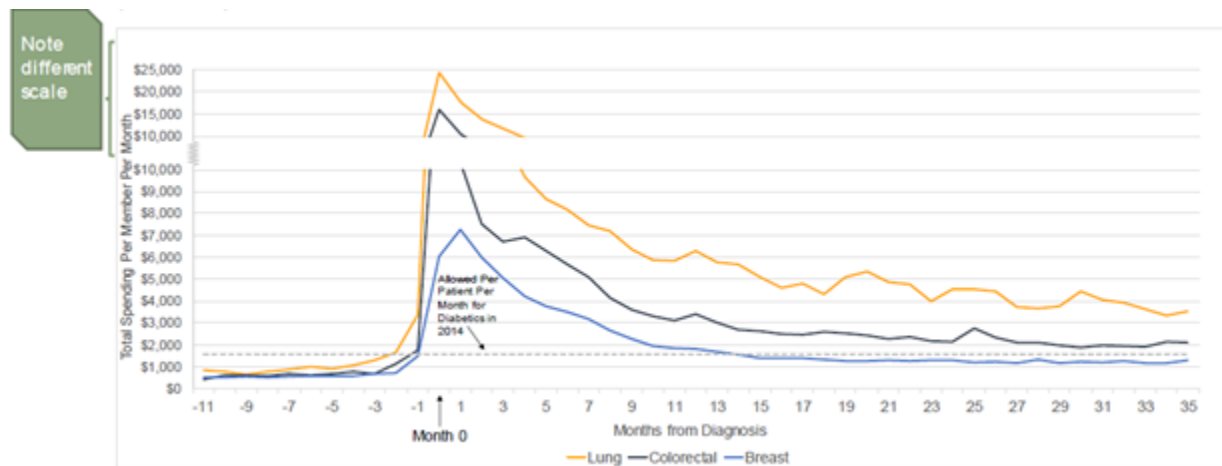


Figure 1: Average monthly healthcare spending, before and after a cancer diagnosis⁵

The Centers for Disease Control and Prevention (CDC), in a survey of more than 10,000 patients, found that roughly one-in-three families reported significant financial burdens as a consequence of medical care. The

degree to which cancer caused financial problems was the strongest independent predictor of quality of life when compared to various other factors, including age, race, education, insurance status, and family income. Interestingly, the study showed that 81% of academic oncologists agreed that out-of-pocket costs had the potential to influence treatment recommendations, but only 30% reported changing treatment recommendations because of financial considerations.

Lung cancer has a high symptom burden and therefore, treatment commencement is of paramount importance to ensure a high quality of life.^{6,7} It is important to note that data in Figure 1 is aggregated data from information from all lung cancer patients. Lung cancer is not one disease, and is, in fact, highly heterogeneous. The two subtypes of lung cancer are non-small cell lung cancer (85%) and small cell lung cancer (15%).² Non-small cell lung cancer is further classified into adenocarcinoma and squamous cell lung cancer. Each of these subtypes of lung cancer has different treatment options available and therefore may have different financial consequences for the patient and their caregiver(s). It is therefore critical to understand how the evolving treatment landscape for lung cancer impacts financial toxicity of patients. This understanding will be crucial in ensuring that access to life-saving drugs is not impeded due to out-of-pocket expenses by developing creative solutions in partnership with regulators and pharmaceutical companies.

In order to catalog financial distress and financial toxicity, LUNGEvity Foundation in partnership with *CancerCare*, surveyed the lung cancer patient and caregiver community. The two patient advocacy groups serve unique communities of patients. The patient community of LUNGEvity Foundation is highly educated and engaged. On the other hand, *CancerCare*'s focus is on the provision of emotional support, financial assistance and education for those in need. Therefore, this study provided a unique opportunity to understand how financial stressors may affect these two unique groups of patient and caregiver community. Some of the specific questions asked in the study were:

1. What financial stressors has a patient (or their caregiver) experienced in the past 12 months?
2. How have these stressors impacted access to care and the patient's treatment journey, as well as their lifestyle?

APPROACH

LUNGeVity Foundation and CancerCare jointly developed a semi-structured survey. Specific domains of the survey included:

1. Financial toxicity experienced in the past 12 months of a patient's (or a caregiver's) lung cancer journey
2. Demographic and background information on past and current diagnostic and treatment journey, including information on biomarker testing and participation in clinical trials. ***These findings are presented in the Appendix.***

The questions were programmed into Qualtrics and deployed online using social media platforms and newsletters of the two organizations. The survey was anonymous, and no identifying information was collected. It was open from May 2018 to September 2018. The study was IRB-approved by Advarra (previously known as Schulman) IRB (Protocol # Pro00025000).

A total of 257 lung cancer patients (190 from LUNGeVity and 67 from CancerCare) and 45 caregivers (37 from LUNGeVity and 8 from CancerCare) were surveyed. For purposes of the study, only differences between participants of the two patient advocacy groups are reported. Patient and caregiver results from each group are presented as aggregates. All data was analyzed using SPSS software. Responses to questions on financial toxicity were coded and used for an ordinal regression model.

MAJOR FINDINGS

As described by Abernathy et al., financial toxicity has two components: the actual financial stress of cancer care as well as the emotional stress associated with high cost of cancer care.³ Patients and caregivers were asked a series of questions about how a lung cancer diagnosis had impacted them financially, including their ability to access healthcare. They also answered a series of demographic questions. Because the differences in responses between the CancerCare respondents and the LUNGeVity responses may be explained, in part, to differences in the demographic profiles of the two groups, we are presenting the demographics first.

Compared to LUNGeVity respondents, CancerCare respondents are more likely to be on Medicare and less likely to have private (employer) health insurance, less likely to be employed for wages and more likely to be on disability, have lower incomes (81% have incomes under \$50,000, while 32% of LUNGeVity respondents have incomes under \$50,000), less likely to be married or in a domestic

partnership, and only half as likely as LUNGeVity respondents to have completed college or professional school. Given these differences and others, it is not surprising that CancerCare respondents' levels of stress from the financial burden of a lung cancer diagnosis are consistently reported at higher levels than those of LUNGeVity respondents. However, LUNGeVity respondents also have financial stress.

Item	Variable	CancerCare	LUNGeVity Foundation	Significant by X ²
Gender	Male	15%	18%	No
	Female	84%	82%	
	Prefer not to disclose	1%	0%	
Age	21-24	0%	0%	No
	25-34	0%	4%	
	35-44	1%	12%	
	45-54	17%	27%	
	55-64	49%	35%	
	65-74	23%	17%	
	75 and older	10%	6%	
	Mean (± Std. Deviation) – in yrs	56 ± 11.8	63.5 ± 9.1	
Are you Hispanic, Latino, or of Spanish origin?	Yes	13%	7%	No
	No	87%	93%	
Race/Ethnicity	American Indian or Alaska Native	3%	0%	Yes
	Asian	1%	3%	
	Black or African American	21%	4%	
	Native Hawaiian or other Pacific Islander	0%	0%	
	White	69%	90%	
	Other	5%	2%	
Health Insurance	Medicare	49%	23%	Yes
	Medicaid	11%	5%	
	Private Medigap	1%	3%	
	Private (employer)	16%	52%	
	Private (Healthcare.gov)	7%	4%	
	Tricare/Champs/VAF	1%	2%	

	I do not have health insurance	3%	1%	
	Others	12%	10%	
Primary language	English	95%	97%	No
	Spanish	3%	2%	
	Others	3%	1%	
Marital status	Single, never married	20%	6%	Yes
	Married or domestic partnership	36%	75%	
	Widowed	19%	7%	
	Divorced	25%	13%	
Employment status	Employed for wages	19%	36%	Yes
	Retired	24%	29%	
	On disability	48%	27%	
	Unemployed	9%	7%	
Annual Household Income	Less than \$25,000	52%	17%	Yes
	\$25,000 to \$49,999	29%	15%	
	\$50,000 to \$74,999	8%	13%	
	\$75,000 to \$99,999	1%	18%	
	\$100,000 to \$124,999	0%	9%	
	\$125,000 to \$149,999	0%	6%	
	\$150,000 to \$199,999	0%	3%	
	\$200,000 or more	1%	7%	
	Prefer not to say	8%	12%	
Education Level	No High School	7%	1%	Yes
	High School or GED	20%	11%	
	Some college or technical school	42%	25%	
	College or graduate/professional school	31%	63%	
Residence	Urban	59%	56%	No
	Semi-urban	30%	32%	
	Rural	11%	13%	

Table 1: Demographic characteristics of the respondents. Significance was determined by X² test and significant differences are indicated in the table in color.

Thinking about the time when you were beginning treatment for lung cancer or during treatment, how distressed (e.g. anxious, extremely upset, or in emotional pain) were you about your finance?

Almost all respondents (95% of the CancerCare group and 90% of the LUNgevity group) reported at least a little distress at the time of treatment commencement or during treatment for their lung cancer diagnosis. **This is distress in general, not specifically financial distress.** Respondents from the CancerCare cohort reported a much higher level of distress (71% were very or extremely distressed) as compared to LUNgevity Foundation participants (46%). On a scale of 1-10 where 1 = not at all distressed and 10 = extremely distressed, LUNgevity Foundation participants reported a **distress score** of 5.51 ± 0.169 as opposed to 6.76 ± 0.246 by the CancerCare group. **An ordinal logistical regression model revealed that LUNgevity participants were 2.4 times less likely to be distressed, as compared to CancerCare respondents.**

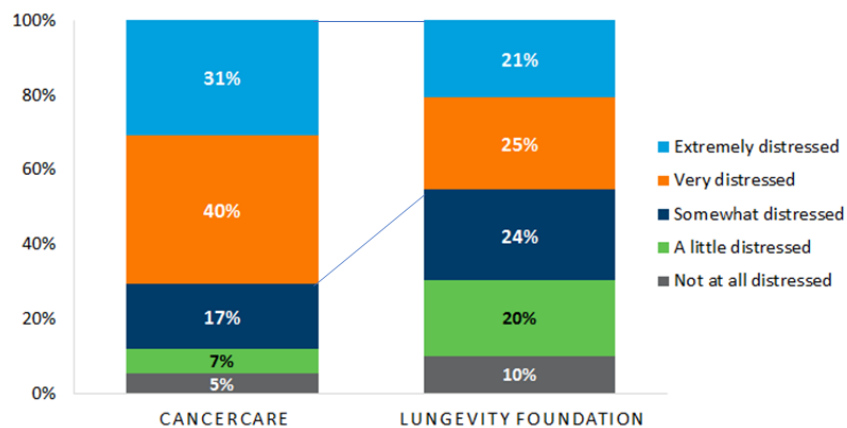


Figure 2: Patient-reported distress levels at the time of treatment commencement or during treatment for their lung cancer diagnosis (*N* = 227 for LUNgevity Foundation and 75 for CancerCare)

Throughout your treatment, to what degree has your cancer treatment caused you financial hardship?

When asked specifically about financial hardship related to the lung cancer diagnosis, about twice as many CancerCare respondents (60%) reported that they experienced either a lot of an extreme amount of hardship as LUNgevity respondents (29%). About three-fourths (72%) of LUNgevity respondents, however, reported at least a little financial hardship, while 92% of CancerCare

respondents reported financial hardship. On a scale of 1-10 where 1 = none and 10 = an extreme amount of hardship, LUNGeVity Foundation participants reported a **financial hardship score** of 4.27 ± 0.182 as opposed to 6.14 ± 0.267 by the CancerCare group. **An ordinal logistical regression model revealed that LUNGeVity participants were 3.4 times less likely to report an extreme amount of financial hardship, as compared to CancerCare respondents.**

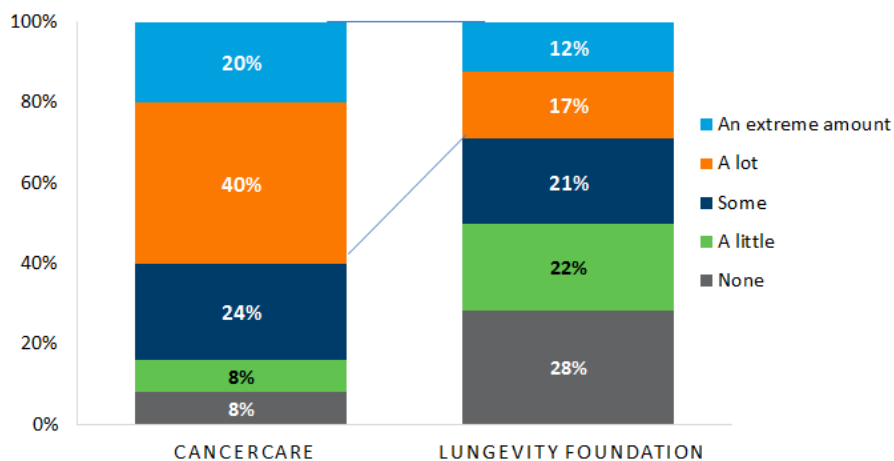


Figure 3: Patient-reported level of financial hardship attributed to lung cancer treatment (N = 227 for LUNGeVity Foundation and 75 for CancerCare)

How severe was this financial hardship for you in the last 12 months?

Not surprisingly, given their higher levels of reported financial hardship, the CancerCare respondents reported high levels of difficulty in managing the financial hardship associated with their diagnosis: 50% of them reported that it was either very difficult to manage them or they were unable to manage them. Twenty-four percent of the LUNGeVity respondents reported these levels of difficulty in managing them. On a scale of 1-10 where 1 = none and 10 = extremely severe financial hardship that is difficult to manage, LUNGeVity Foundation participants reported a **financial hardship coping score** of 4.68 ± 0.14 as opposed to 6.12 ± 0.237 by the CancerCare group. **An ordinal logistical regression model revealed that LUNGeVity participants were 3.5 times less likely to report an extreme amount of financial hardship that they were unable to manage, as compared to CancerCare respondents.**

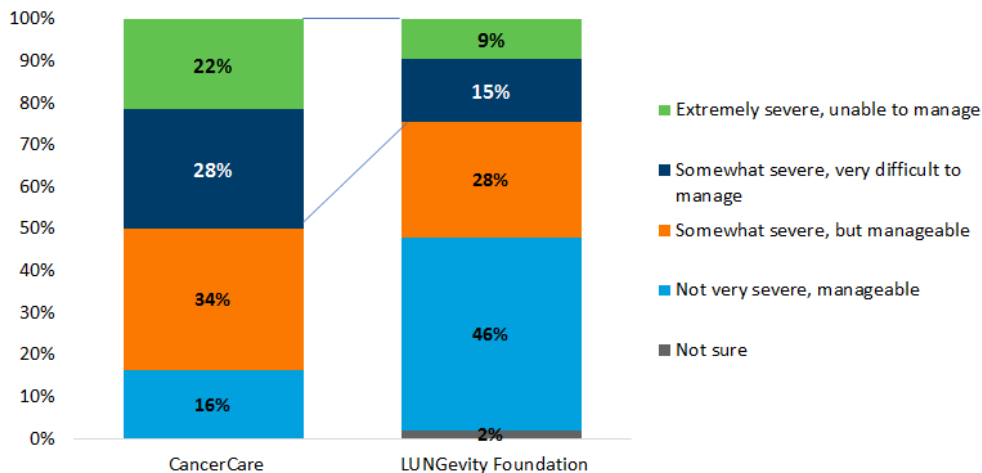


Figure 4: Patient-reported ability to cope with financial hardship attributed to lung cancer treatment (N = 213 for LUNgevity Foundation and 74 for CancerCare)

Financial stresses can be understood in three fronts:

1. **Out-of-pocket expenditures for medical care** – co-pays, coinsurance, deductibles, premiums – and related non-medical expenses
2. **Third Party Loss** – Potential loss of household income of other family members due to caregiving needs. Insert actual question about out-of-pocket health-related expenses
3. **Other Consequential costs** – Loss of earnings for the affected individual - and sometimes loss of access to insurance.

Major out-of-pocket expenses reported in the last 12 months

When presented with a list of out-of-pocket health-related expenses they might have had to pay for in the last 12 months that might have contributed to respondents’ financial distress, the highest for both groups were transportation to the hospital or treatment site (55% of CancerCare respondents and 42% of LUNgevity respondents). Other medication to manage pain or other side effects, office visits to primary care physician or oncologist, and prescription medications specific to their cancer treatment were the next most-often reported expenses from the list for both groups.

Out-of-pocket expense item	CancerCare	LUNgevity Foundation
Transportation to the hospital or treatment site	55%	42%
Other medication to manage pain or other side-effects	46%	36%
Office visits to primary care physician or oncologist	42%	40%
Prescription medications specific to your cancer treatment	41%	40%
Hospital bills	33%	28%
Other medical providers (anesthesiologist, radiologist, pathologist, ambulance services, etc.)	32%	27%
Laboratory services, such as blood, or urine testing	30%	27%
Radiology services such as CT scans or X-rays	29%	33%
Other, please specify	20%	25%
Urgent care or emergency visits	19%	15%
Lodging while traveling for treatment	13%	18%
Diagnostic test such as biomarker testing of your tumor	7%	14%
Outpatient rehabilitation, skilled nursing, or other outpatient facility	7%	4%
All of the above	4%	3%
Surgery	1%	8%
Inpatient rehabilitation, skilled nursing, or other in-patient facility	1%	1%

Table 2: Respondent-reported out-of-pocket health related expenses in the last 12 months contributing to financial distress (N = 205 for LUNgevity Foundation and 69 for CancerCare)

In the last 12 months, which specific costs would you say contributed the most to your overall out-of-pocket expenses for your treatment?

Respondents then had the opportunity to name in their own words the biggest contributors to their out-of-pocket expenses over the past 12 months. These responses were then categorized into seven major themes. Most of these categories are health-related expenses. Expenses related to health insurance (co-pays, deductibles, premiums, etc.) were named most often by both groups, 38% of CancerCare respondents and 47% of LUNgevity respondents. There were two types of expenses one health-related and the other one not, that seemed of much more concern to CancerCare respondents: transportation-related expenses to access treatment (36%), but only 19% of LUNgevity respondents, and household expenses (including rent and mortgage payments, groceries, and utility bills (29% of CancerCare respondents but only 9% of LUNgevity respondents).

Theme	CancerCare	LUNgevity Foundation	Representative Quotes
Healthcare expenses not related to treatment (e.g. doctor visits, hospital visits,	22%	29%	Payments at all my doctors' visits

diagnostic and laboratory tests, etc.)			
Treatment-related expenses (e.g. purchase of drugs, medical procedures such as surgery, etc.)	24%	33%	Cost of targeted therapy--insurance company changed the drug Tier for coverage and I suddenly became unable to get the drug as I had the previous 2 years.
Other healthcare expenses related to symptom and side-effect management (e.g. complementary care, pain medication, etc.)	13%	12%	I pay 20 percent of all medical bills affiliated with treatment and pay full price for medication...calcium with vitamin D. for cancer in bones needed for shot I take every 6 weeks
Transportation-related expenses to access treatment	36%	19%	Travel - airfare & hotel costs for treatment at The James
Expenses related to health insurance (Co-pays, deductibles, premiums, etc.)	38%	47%	Co-pays for treatments, testing, doctors, medications etc.
Loss of income due to cancer diagnosis and treatment	11%	6%	Time missed from work to transport my parent to treatment, transportation costs to drive my mom 2.5 hours down the PA turnpike every 3 weeks.
Household expenses including rent and mortgage payment, groceries and utility bills	29%	9%	I see no way to pay for the services received. There are many debt collection agencies calling and writing me. The amounts continue to mount up with no possible way to pay these bills. And because the medications effect my mind/body I am unable without help to deal with all of the actual billing/bookkeeping/financial records as well as all of the requirements of daily living.

Table 3: “In their own words” - Respondent-reported out-of-pocket health related expenses (N = 154 for LUNgevity Foundation and 45 for CancerCare)

What impact did the financial hardship have on your medical care in the last 12 months?

While healthcare expenses impacted the healthcare-seeking behavior of both sets of respondents, clearly these expenses affected the CancerCare respondents much more: 44% of them reported that the expenses had no impact on their medical care, while 77% of LUNgevity respondents reported no impact. Twenty-five percent of CancerCare respondents reported that the expenses forced them to change the way they pay for care (switching from insurance to charity care, for example). Only 7% of LUNgevity respondents reported this change. Other ways in which both sets of respondents changed their behavior, more so the CancerCare respondents for all ways, were shifting their care to a different treatment location, stopping or postponing treatment, and not following medical advice as prescribed.

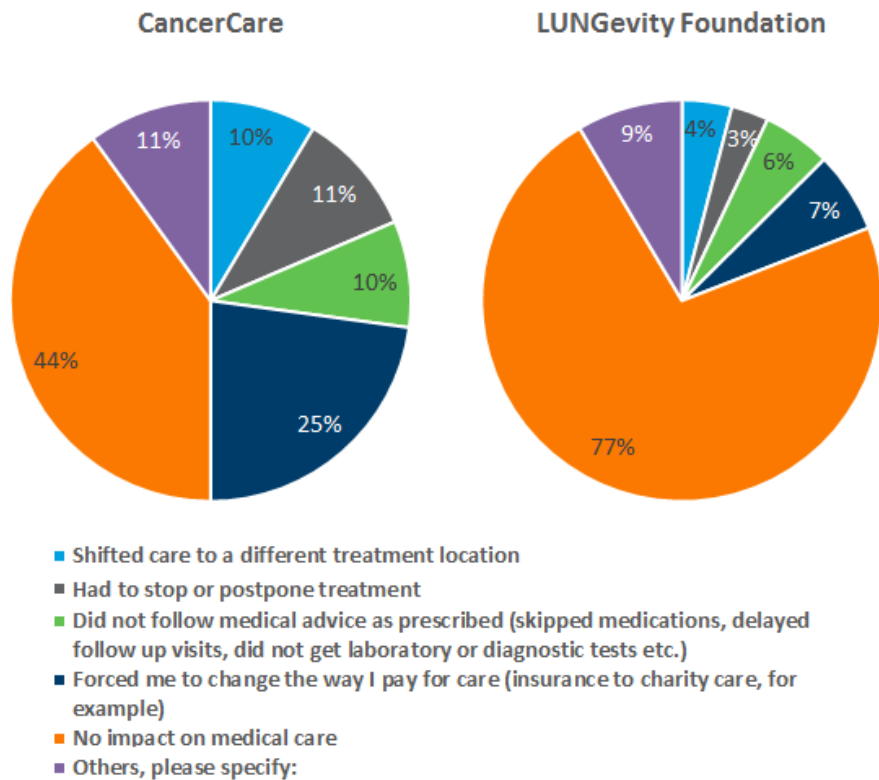


Figure 5: Impact of healthcare expenses on health-seeking behavior (N = 188 for LUNgevity Foundation and 63 for CancerCare)

What impact did the financial hardship have on your daily living and lifestyle in the last 12 months?

Healthcare expenses also have an impact on daily living. Presented with a list of ways that they might have an impact, both CancerCare and LUNgevity respondents selected a number of ways. Again, CancerCare respondents were more likely to select an impact: only 11% of them reported that healthcare expenses had no or little impact, while 47% of LUNgevity respondents reported this. Among both sets of respondents, cutting or reducing other non-critical household expenses was the most frequently reported impact: 55% of CancerCare respondents reported this, while 42% of LUNgevity respondents reported it. Most striking were the differences between the two groups in being forced to borrow from family/friends (44% of CancerCare respondents, 16% of LUNgevity respondents), utility bills being paid late (43% of CancerCare respondents, 11% of LUNgevity respondents), and being unable to afford groceries (32% of CancerCare respondents, 9% of LUNgevity respondents).

Impact on lifestyle	CancerCare	LUNgevity Foundation
I cut or reduced other non-critical household expenses	55%	42%
I was forced to borrow from family/friends	44%	16%
My utility bills were paid late	43%	11%
I was unable to afford groceries	32%	9%
I cut or reduced critical household expenses (house repair, car repair, etc.)	32%	22%
I was forced to use credit cards or bank loans that I would not otherwise have used	27%	19%
I missed rent or mortgage payments	19%	5%
I had to sell other assets	16%	11%
My utilities (water, electricity, phone, etc.) were turned off	11%	4%
No or little impact	11%	47%
I (or a member of my household) had to obtain additional employment	9%	5%
I moved in with a family member	9%	4%
I filed or am in the process of filing for bankruptcy	7%	1%
Others, please specify	7%	5%
I missed car payment(s)	5%	6%
I was forced to sell my home	4%	2%
I had to sell my car	4%	3%
I was evicted from my apartment or house	1%	1%
I lost my home due to foreclosure because I couldn't pay my mortgage	0%	0.4%
My home was foreclosed on (taken over by the bank)	0%	0.4%

Table 4: Impact of healthcare expenses on daily living (N = 226 for LUNgevity Foundation and 75 for CancerCare)

Which of the following have you experienced as a direct result of bills related to your cancer treatment?

A high proportion of CancerCare respondents reported seeing financial assistance to offset the living expenses that they were unable to meet because of their high healthcare costs. They were roughly twice as likely as LUNgevity respondents to name each of the types of financial assistance. Both sets of respondents were most likely to apply for financial assistance from a patient support organization (58% of CancerCare respondents and 24% of LUNgevity respondents).

Support mechanism to offset impact of healthcare costs in past 12 months	CancerCare	LUNgevity Foundation
I asked for financial help from a church or community organization	29%	11%
I applied for financial assistance from a patient support organization	58%	24%
I borrowed money from family/friends	44%	23%
I applied for financial assistance from my doctor's office or hospital	34%	18%

Table 5: Patient-reported coping mechanism for high financial stress (N = 226 for LUNgevity Foundation and 75 for CancerCare)

Has a member of your cancer care team ever asked if you were feeling distressed about specific issues?

Healthcare provider-initiated discussion about financial toxicity and its impact on a patient’s well-being can help mitigate the distress associate with high cancer care costs as well as be a source of information for support services that the patient can access. Both sets of respondents reported a wide range of discussed concerns (the most discussed topic was side effects of the treatment), More of the CancerCare respondents (63%) reported discussing financial challenges, such as paying bills, than LUNgevity respondents (45%), but more of the LUNgevity respondents (44%) discussed treatment payment and insurance coverage than CancerCare respondents (35%). Only 65% of respondents from both groups reported that their cancer care team discussed any form of financial issues.

Discussion item	CancerCare	LUNGevity Foundation
Side effects of your cancer treatment	66%	78%
Worry or anxiety about the future	63%	66%
Financial challenges (Paying bills, etc.)	63%	45%
Activities of daily living	53%	46%
Hair loss and/or body image	42%	33%
Treatment payment and insurance coverage	35%	44%
Lifestyle concerns	32%	36%
End of life concerns	31%	27%
Being a burden to my loved one	26%	22%
Work-related concerns	23%	33%
Concerns related to your relationship with your family	21%	23%
Sexual/intimacy concerns	8%	17%

Table 6: Patient-reported coping mechanism for high financial stress (N = 179 for LUNGevity Foundation and 62 for CancerCare)

CONCLUDING THOUGHTS

Rising costs of drugs is no secret that people find it difficult to afford their prescription medications – especially cancer patients facing the expenses of specialty drugs. An average patient can expect out-of-pocket expenses to be between 20% to 30%. Very few insurance plans cover all of the costs in full. The stress and burden of facing these out-of-pocket costs leads to financial toxicity. The results described in this survey clearly suggest that a lung cancer diagnosis is a financial stressor for both patients and caregivers, given the high cost of lung cancer care.

When comparing which group was impacted extensively from the cancer treatment, 60% of CancerCare respondents reported a high level of financial hardship, as compared to 29% of LUNGevity respondents - Figure 3. As explained above, these differences may be attributed to, in large part, due to the demographic differences between the two groups.

Race and ethnicity – The CancerCare cohort is racially more diverse and has a higher number of African American respondents. Studies in breast cancer have demonstrated that race as a single variable is a determinant of risk of financial toxicity.⁸

Health insurance – LUNGevity respondents were more likely to have private employer-provided insurance. The contribution of health insurance to financial toxicity is multi-factorial. A recent study by Zafar,

Peppercorn et al. assessing out-of-pocket expenses and the insured cancer patient's experience concluded that having health insurance does NOT eliminate financial distress among cancer patients.⁹ Our findings showed that *CancerCare* patients were predominately funded by public payors (Medicaid and Medicare) compared with LUNGeVity patients. In addition, it is reported that about one-in-five older cancer patients report experiencing financial toxicity, according to researchers from the University of Rochester in New York.¹⁰ Most of these older patients are funded by Medicare that doesn't cover adequate Medicare part C and D benefits further aggravating the financial toxicity for elder patients. Indeed, the *CancerCare* cohort has a higher percentage of Medicare patients (33%) as compared to LUNGeVity (23%). Furthermore, 81% percent of respondents from *CancerCare* are above the age of 55 years, as compared to LUNGeVity Foundation (58%). In an analysis conducted by National Minority Quality Forum, based on 2016 Medicare FFS claims data for all patients (N=272,772) with an ICD 10 diagnosis code of lung cancer, out-of-pocket cost for all beneficiaries was \$287,425,639, with 10% of beneficiaries paying over \$2,050 to the maximum of \$234,601.¹¹

Employment status – A higher proportion of *CancerCare* respondents report being on disability, as compared to LUNGeVity respondents (which may also explain a lower percentage of respondents with employer-provided insurance)

Income and education levels – Eighty-one percent of *CancerCare* respondents reported having an annual household income of less than \$50,000, as compared to 32% of LUNGeVity Foundation respondents. Furthermore, the *CancerCare* cohort members are only half as likely as LUNGeVity respondents to have completed college or professional school. Both household income as well as education levels are associated with the risk of developing financial toxicity.¹²⁻¹⁴

Though the factors described above have been related to an increased risk of financial toxicity, it should be noted that no singular factor noted above should be considered as the sole contributor to a higher level of financial distress in the *CancerCare* cohort. It is highly likely that factors listed about interact with and influence each other to cumulatively produce higher levels of psychosocial distress in the *CancerCare* cohort – a concept known as intersectionality. In fact, when our regression model was adjusted for race and income levels, LUNGeVity respondents were still more likely to report lower levels of financial distress as compared to *CancerCare* respondents. For providers and patients, an honest and frank discussion on the cost of therapy is being communicated.

What does this mean for patients and caregivers? Our study demonstrates that financial concerns are top-of-mind for all lung cancer patients. The impact of financial toxicity not only impacts healthcare-seeking behavior such as decreased access to treatment and clinical trials but has devastating impact on a patient's daily living. It is important to note that only 65% of patients reported that their healthcare team discussed issues related to financial toxicity, though most seemed to engage in shared decision-making. While there are no quick fixes to ensure that the burden of financial toxicity is minimized, a first step is to promote candid discussions between patients and physicians. Several pharmaceutical companies have co-pay and patient assistance programs and healthcare teams should share such information with their patients.

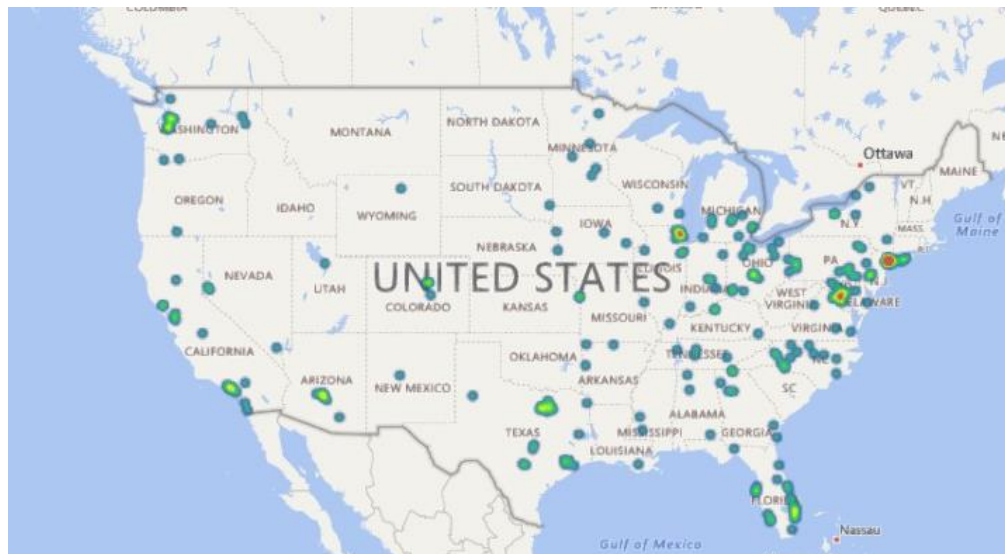
At a policy level, Federal Reforms including Affordable Care Act, may hold key to solving the problem of financial toxicity through its provisions that help limit the financial burden of medical care. Unfortunately, it may have the unintended consequence of actually increasing the financial toxicity by causing expansion of high-deductible health plans. In addition, if an insurance plan purchased through a health care exchange does not cover care at a major cancer center, the patient may be faced with high out-of-pocket costs that will not be part of the annual limitation on cost-sharing. However, the latest revolution of Medicaid innovation waivers where state policy makers are increasingly focused on social determinants of health (SDOH) because of the important influence of these determinants on health care outcomes and Medicaid spending may prove to be an indirect intervention of financial toxicity. Social determinants include a broad array of social and environmental risk factors such as poverty, housing stability may be another intervention that could solve for a lot of the challenges associated. In summary, a one-size-fits-all solution is not possible for a problem as complex and nuanced as financial toxicity. All solutions should take into account not just the patient's diagnosis, but the structural and societal context of the disease.

LIMITATIONS OF THE CURRENT STUDY

We noted the following limitations of the study:

1. Under sampling of CancerCare: Despite several outreach efforts, the sample size of the CancerCare cohort (N=76) is significantly smaller than the LUNGEvity cohort (N = 227). This may be due to intrinsic levels of engagement and self-selection for participation in such studies between the constituents of the two organizations.
2. Under sampling of caregivers: Our study does not include a robust sample of caregivers.

3. Racial and ethnic, and geographical representation of patients and caregivers: Though the CancerCare cohort is racially and ethnically more diverse than the LUNgevity cohort, the composition doesn't reflect the US demographic. As such, perspectives provided in this analysis should not be misconstrued as representing the minority voice but rather provides us directional information on the complexity of the problem. In addition, as evident from the map below (respondent zip codes are marked), majority of the respondents were drawn from East Coast of the US – where the participating advocacy organizations are located.



Despite these limitations, our study uncovers the burden of financial toxicity in both an engaged and educated (LUNgevity Foundation respondents) and a more disenfranchised population (CancerCare respondents) of lung cancer patients and caregivers and calls for more support systems for lung cancer patients and caregivers, such that they can continue to receive high quality care.

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Appendix

All additional findings are summarized in the Appendix

In which year were you diagnosed?

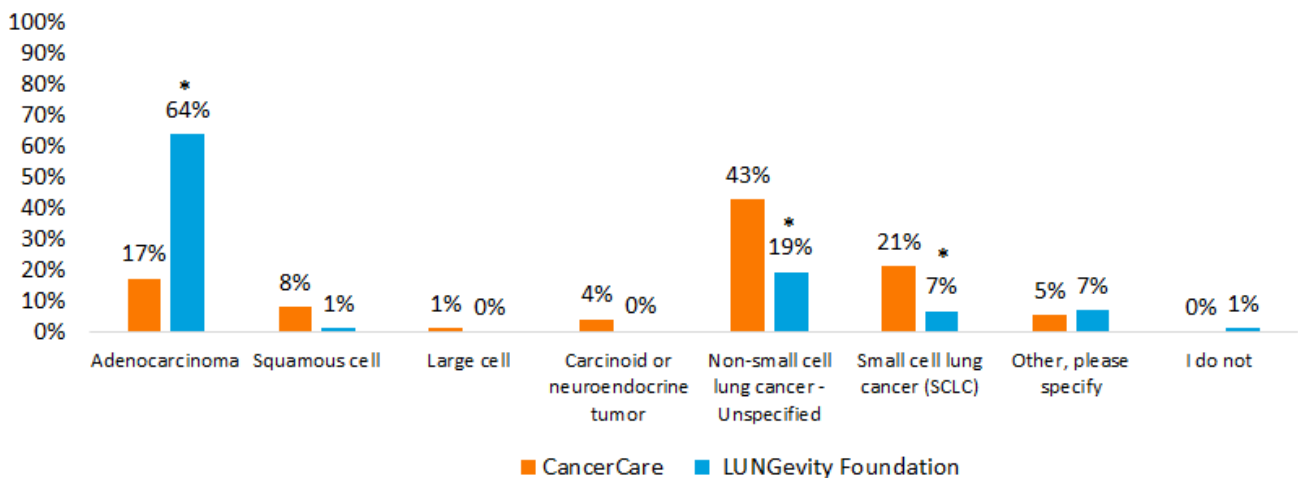
The majority of both CancerCare and LUNGevity patients were diagnosed within the past four years.

CancerCare	
Year	Percentage
1997	1%
2003	1%
2011	3%
2012	1%
2013	4%
2014	7%
2015	14%
2016	23%
2017	38%
2018	8%

LUNGevity Foundation	
Year	Percentage
1996	0.45%
2001	0.45%
2004	0.45%
2005	0.45%
2006	0.45%
2007	0.45%
2008	1%
2009	2%
2010	2%
2011	2%
2012	5%
2013	10%
2014	12%
2015	13%
2016	17%
2017	27%
2018	6%

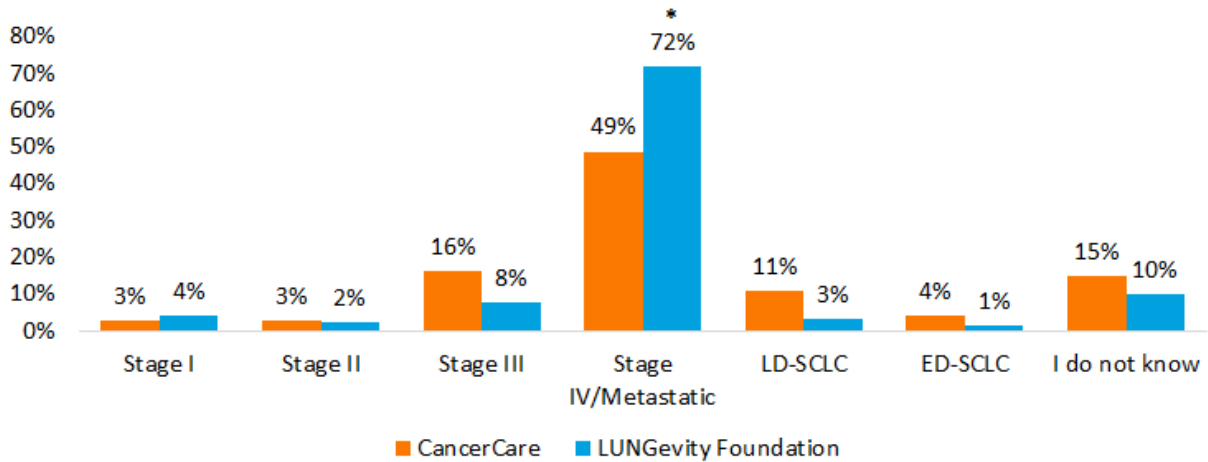
Histology of lung cancer

CancerCare patients were much less likely to know their subtype of non-small cell lung cancer than LUNGevity patients. CancerCare patients were much more likely to have small cell lung cancer than LUNGevity patients. This may have to do with the risk factors to which these CancerCare patients were exposed; see the next section. ** indicates a significant difference between the two groups.*



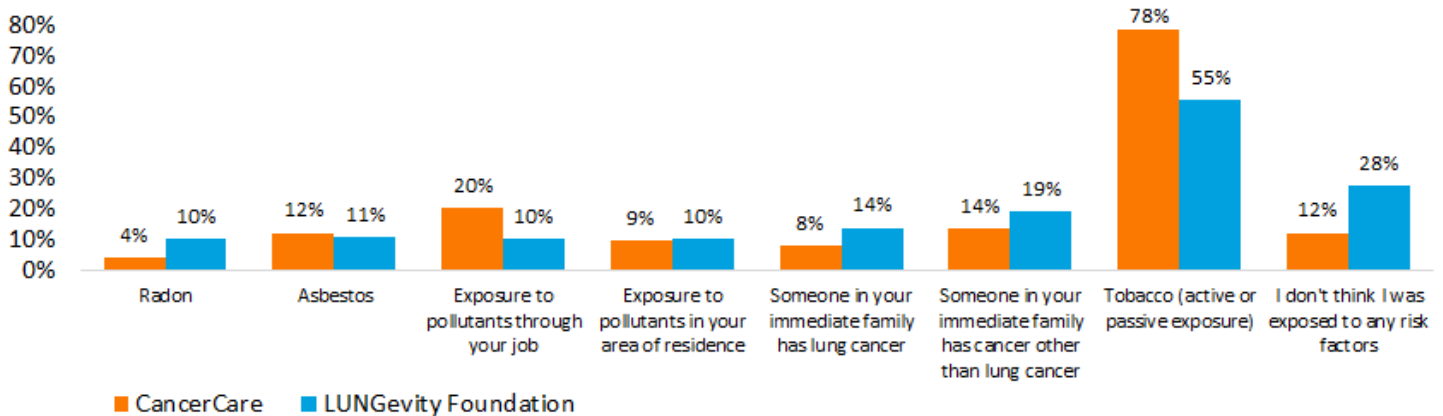
Stage of lung cancer

Participants from the LUNgevity cohort reported a higher incidence of stage IV/advanced-stage/metastatic NSCLC (72%) as compared to the CancerCare cohort (49%). However, this finding alone is not sufficient to explain the higher rate of targeted therapy usage in the LUNgevity cohort. ** indicates a significant difference between the two groups.*



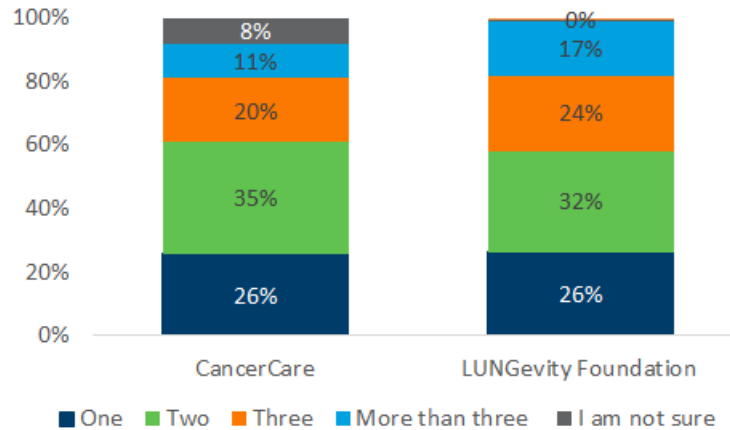
Exposure to known risk factors for lung cancer

CancerCare patients (78%) were more likely to have been exposed to tobacco, either actively or passively, than LUNgevity patients (55%). They also were twice as likely (20%) to have been exposed to pollutant through their job than LUNgevity patients (10%); this may at least partially explain why CancerCare patients were more likely to have small cell lung cancer.



Lines of treatment received by respondents

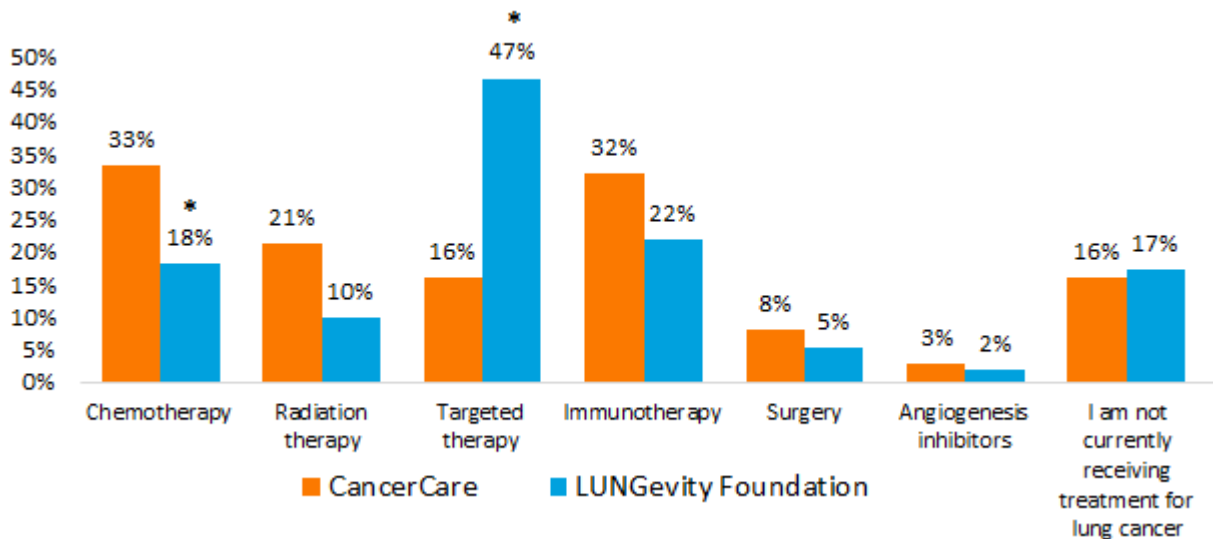
There was very little difference in the number of lines of treatment that CancerCare and LUNgevity patients received; the largest number of each, around one-third, reported that they had two lines of treatment.



Current treatment being received

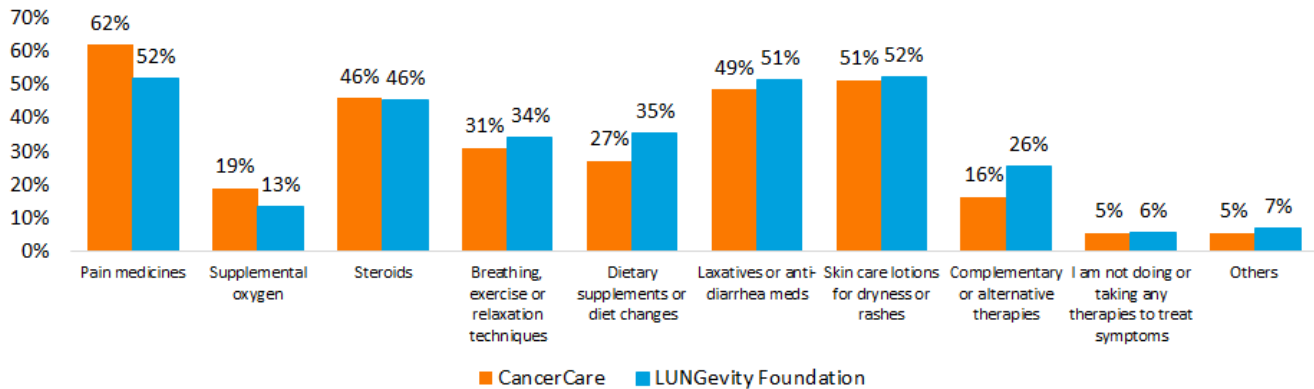
LUNgevity patients (47%) are three times as likely to be receiving a targeted therapy than CancerCare patients (16%), while CancerCare patients (33%) are almost twice as likely to be receiving chemotherapy than LUNgevity patients (18%). This may be in part related to the earlier finding (see figure 2) that LUNgevity patients were more likely to specify that they had adenocarcinoma than CancerCare patient as well as to the finding (see Figure 6) that more of the LUNgevity patients (72%) patients have stage IV/metastatic non-small cell lung cancer than the CancerCare patients (49%).

** indicates a significant difference between the two groups.*



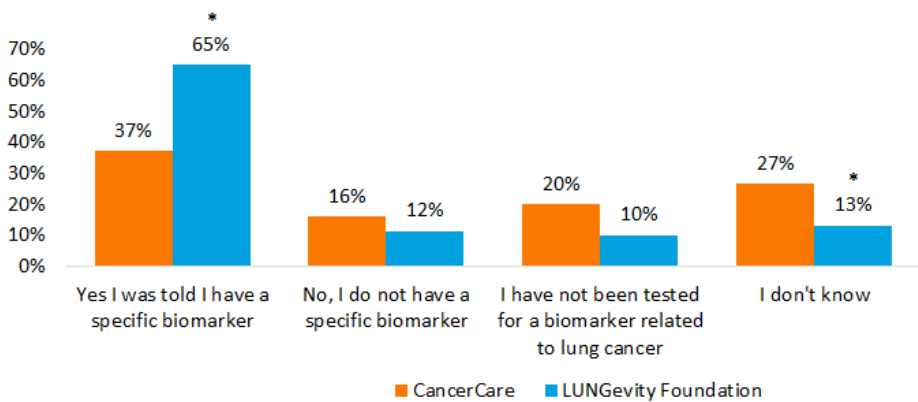
Additional treatments being received for symptom and side-effect management

The additional treatments sought out by both CancerCare and LUNGevity patients were about the same. Pain medications, skin care lotions for dryness or rashes, and laxatives or anti-diarrhea medications were the treatments most often used.



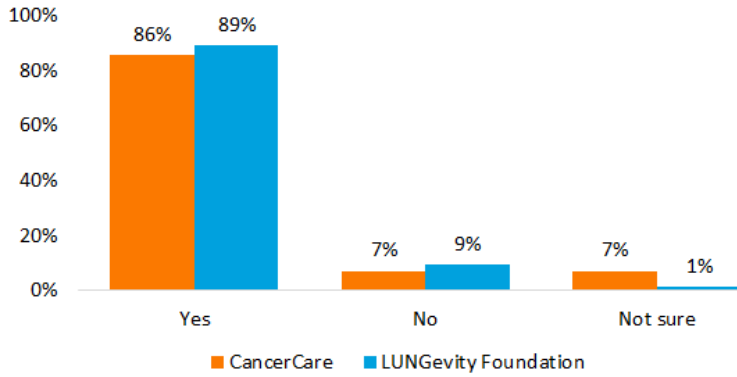
Have you (or your loved one) undergone biomarker testing?

CancerCare patients were less likely to have been tested for biomarkers or not know if they were tested. Two-thirds (65%) of LUNGevity patients were told that they have a specific biomarker, while only 37% of CancerCare patients were told this. * indicates a significant difference between the two groups.



Did the treating physician discuss the results of biomarker testing?

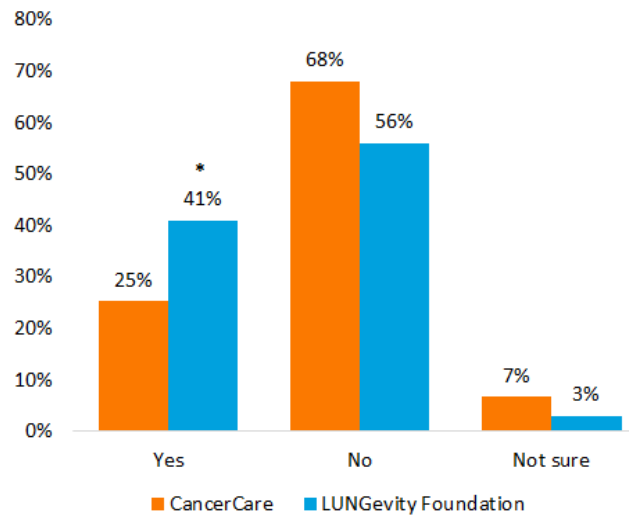
Of the patients who underwent biomarker testing, most (85% of CancerCare patients and 89% of LUNGevity patients) reported that their treating physician had adequately explained the biomarker test results to them. Almost half of both CancerCare and LUNGevity patients reported that they have an EGFR mutation. LUNGevity patients were better able to identify other mutations; “others” were reported by 41% of CancerCare patients, but only 9% of LUNGevity patients.



Biomarker	CancerCare	LUNGeVity Foundation
ALK	7%	26%
BRAF	0%	2%
EGFR	44%	47%
HER2	0%	1%
KRAS	0%	8%
MEK	0%	0%
MET	0%	3%
PD-L1	15%	16%
PIK3CA	0%	3%
RET	0%	1%
ROS1	0%	5%
Others	41%	9%

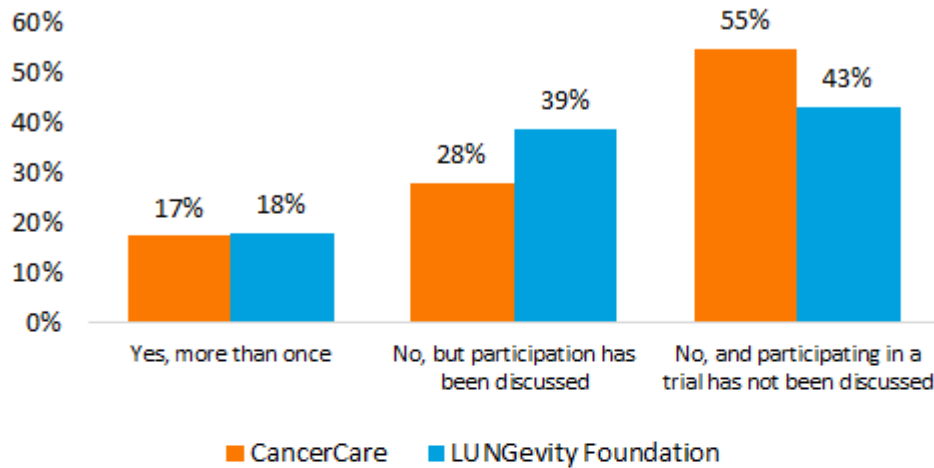
Did the treating physician offer the option of participating in a clinical trial?

The physicians of LUNGeVity patients were more likely (41%) than those of CancerCare patients (25%) to have provided the option of participating in a clinical trial to them. * *indicates a significant difference between the two groups.*



Respondent-reported rates of participation in clinical trials

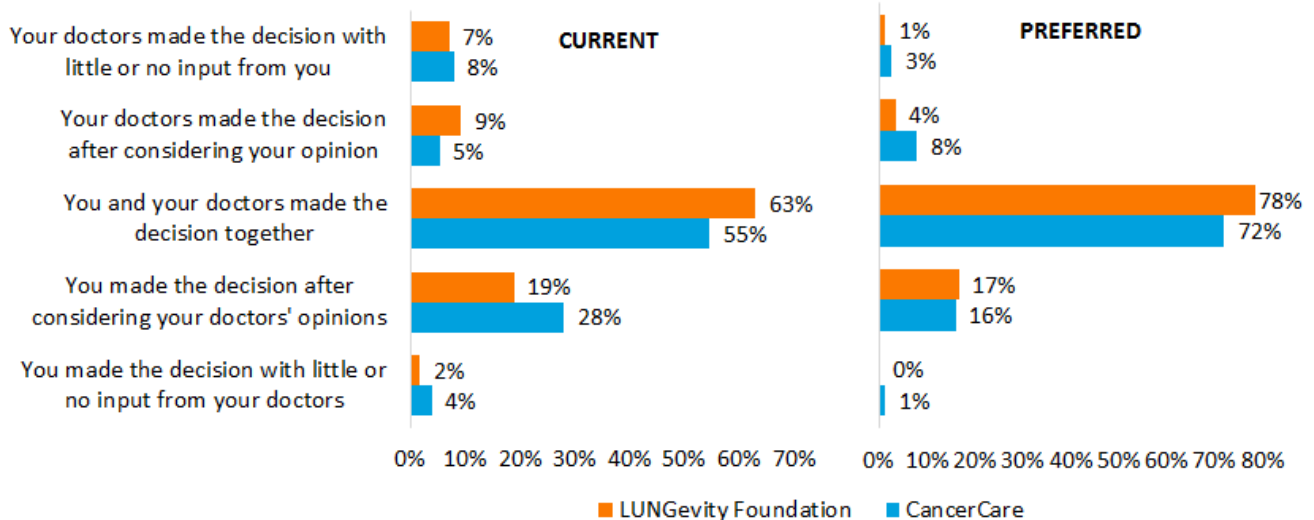
Similar rates of clinical trial participation were reported by CancerCare patients (17%) and LUNGeVity patients (18%). The reason why not most often reported among those who did not participate in a clinical trial was that their doctor did not recommend it (30% of CancerCare patients and 25% of LUNGeVity patients). While the percentages were not high, CancerCare patients were more likely than LUNGeVity patients to report that they did not have enough information on it and that out-of-pocket costs and transportation issues were among the reasons why not.



Reason	CancerCare	LUNGeVity Foundation
My doctor doesn't recommend it	30%	25%
I would have to change doctors	6%	3%
I don't want to be a guinea pig	8%	3%
The medications are untested	5%	3%
I don't have enough information on it	23%	12%
Out-of-pocket costs	17%	7%
Time commitment	9%	3%
Transportation issues	12%	5%
Travel distance from home	14%	10%
Others	39%	59%

Do respondents prefer shared decision-making?

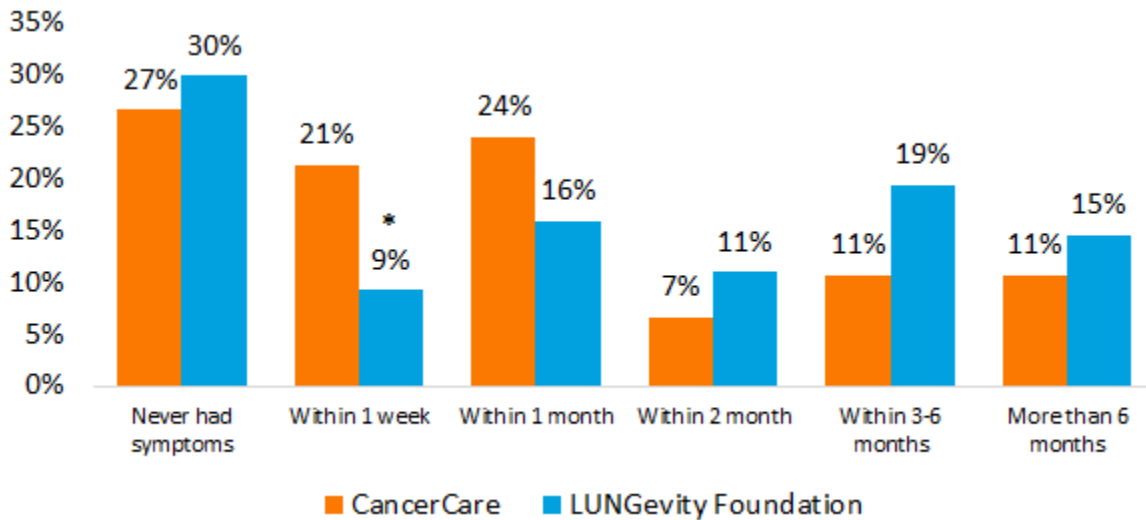
LUNGeVity patients are a bit more likely than CancerCare patients to actually share decision-making with their doctor and to prefer to share decision-making. Shared decision-making was less often the actual method than it was the preferred method.



Was there a delay in diagnosis?

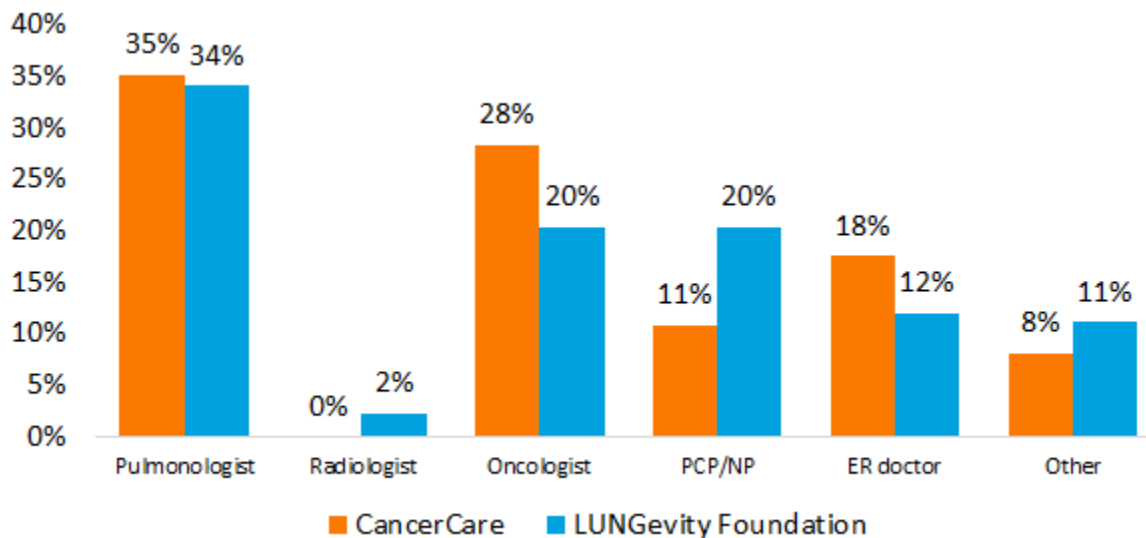
Among those who had symptoms, the majority of CancerCare patients received their diagnosis within one month, while the majority of LUNgevity patients received their diagnosis within two months.

** indicates a significant difference between the two groups.*



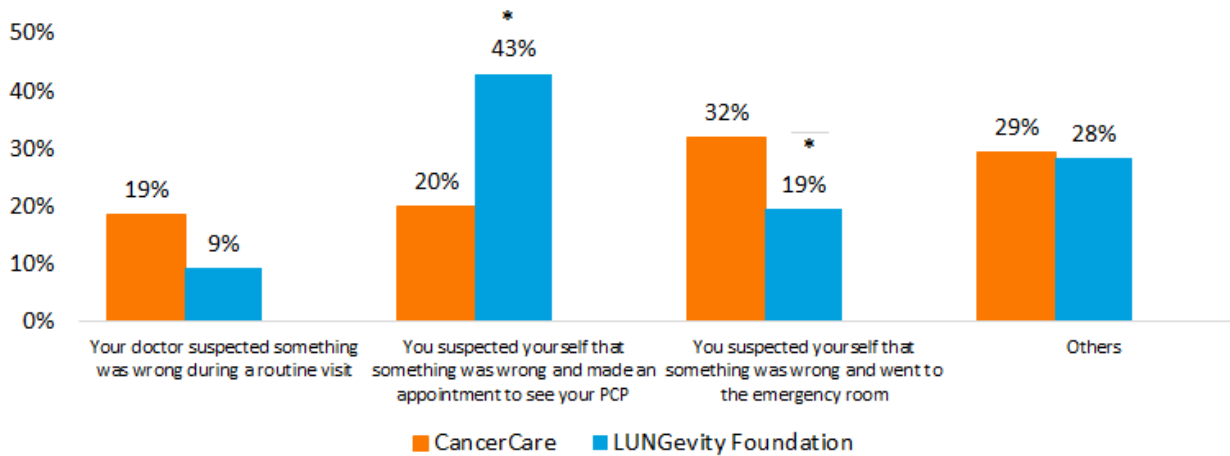
Who made the initial diagnosis of lung cancer?

About one-third of both CancerCare and LUNgevity patients were given their initial lung cancer diagnosis by a pulmonologist. Next most likely for both groups was an oncologist.



What triggered you to think that you may have lung cancer?

LUNgevity patients (43%) were significantly more likely than CancerCare patients (20%) to have suspected themselves that something was wrong and made an appointment to see their primary care provider. However, CancerCare patients were significantly more likely (32%) than LUNgevity patients (19%) to suspect themselves that something was wrong and go to the emergency room. It may be that CancerCare patients are less likely to have a regular primary care provider, but we don't have that information. ** indicates a significant difference between the two groups.*



If you were not diagnosed by your oncologist, were you referred to one immediately?

Three-fourths of both CancerCare patients and LUNgevity patients reported that they were immediately referred to an oncologist following their diagnosis. (Reactive = referred by healthcare team, Proactive = self-referral by patient or loved on)

