

Understanding the experience of living with non–small-cell lung cancer (NSCLC): a qualitative study

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Background As non–small-cell lung cancer (NSCLC) treatments improve and patients live longer, it is important to develop interventions to help patients live fuller lives. We sought to identify key components of quality of life (QOL) in determining therapeutic decision making and overall value of life extension in patients with NSCLC.

Methods Three focus groups (n = 16) and telephone interviews (n = 15) were conducted with NSCLC patients (N = 31) to explore symptoms considered important to QOL. A trade-off format was used to assess the value of life extension relative to QOL. Patients were asked to consider a hypothetical treatment option offering a modest (3 month) life extension.

Results Patients' mean age was 61.6 years, 67.6% were women, 77.4% were white, and 48.4% had stage III/IV disease. In all, 68% of patients conceptualized emotions as symptoms of NSCLC. Key symptoms changed over time: Patients reported feeling shock and fear at diagnosis (74%), and feeling fear or loneliness during the beginning of therapy (55%). Additionally, patients who reported successfully connecting with other NSCLC patients (peers), support groups, and/or community members reported a positive shift in feelings (52%) as they continued therapy or moved into a posttherapy phase. Financially, 23% of patients reported being adversely affected by copayments, 36% by unexpected gaps in coverage, and 39% by other bills. Patients reported that the most important dimension driving their decision making about life-extending therapy was somatic (84%), followed by functional (32%), relational (23%), and emotional (10%) dimensions.

Limitations Study participants were likely to have received some education or support from the recruiting cancer advocacy and patient education/support organizations. In addition, participants were of a higher socioeconomic status than the average lung cancer patient population.

Conclusions Patients with NSCLC conflated emotional well-being after diagnosis with symptoms of their cancer and treatment toxicities. Somatic QOL concerns emerged ahead of functional, emotional, and relational QOL concerns as the dominant driver of therapeutic decision making.

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Lung cancer is the most common cancer worldwide and accounts for the most cancer-related deaths in the United States.¹ Approximately 85% of all lung cancer is characterized histologically as non–small-cell lung cancer. NSCLC is often undetected until symptoms develop and the patient presents with advanced disease;² because of this, overall 5-year survival rates are low (16%). Consequently, the goals of treatment for advanced NSCLC include extending progression-free survival and reducing the severity of symptoms.

Although medical researchers and oncologists are striving to better understand, diagnose, and treat NSCLC, comparatively little research

and resources have been devoted to studying and addressing the unmet emotional and psychosocial needs experienced by these patients. In general, outcome research in lung cancer has focused predominantly on short-term survival and other clinical outcomes, leading to a lack of knowledge surrounding lung cancer survivorship and quality of life (QOL).³

Studies that have examined the social and emotional experiences of lung cancer patients have found that these patients report higher levels of distress, compared with individuals who have other cancers.⁴ For example, lung cancer patients report significant levels of distress (43%), compared with

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breast cancer patients (32%) and colon cancer patients (32%). Cross-sectional studies have suggested that elevated and untreated distress can lead to a lower QOL, lower satisfaction with medical care, worse treatment adherence, and decreased survival.^{5,6} As a means of addressing this issue, the Institute of Medicine, the National Comprehensive Cancer Network, and the American College of Surgeons have recognized that screening, referral, and follow-up for emotional, physical, and social concerns are critical to ensuring quality cancer care.⁷⁻⁹ A number of validated measures can be used to assess cancer-related distress^{7,9-14} and identify areas of unmet clinical need.¹⁵⁻¹⁹

One distress-screening tool is the Distress Thermometer (DT), a single-item visual analog tool that screens for distress in cancer patients.⁸ It is a validated measure with an established cutoff score^{3,4} indicative of clinically significant levels of distress. Another tool is CancerSupportSource (CSS), an evidence-based, validated, psychosocial distress-screening program that was designed for community practice settings. CSS integrates a valid and reliable self-report measure with automated linkages to vital information and referral for support services. CSS asks patients to rate their current concerns, and to identify the specific type of assistance they desire to address those concerns (ie, talk to a staff member, referral to online resources, quality information, or no help). Both DT and CSS are sensitive and specific measures to detect distress in cancer patients.

Despite the availability of general cancer distress-screening tools, specific cancer groups commonly express specific sources of distress that may not be captured by these general measures. Thus, we sought to understand if there were particular needs and sources of distress for patients living with NSCLC that might be used to inform the development of screening tools for NSCLC patients.

Now more than ever, health care systems, practices, and physicians rely on patients to play a more active role in their care, accepting more responsibility and becoming more involved in decision-making processes.²⁰ At the same time, the advent of new targeted therapies means that the number of cancer treatment options is increasing and becoming more complex. For patients living with advanced NSCLC, the goal of treatment is to extend both progression-free survival and overall survival. Thus, some of the treatment options that patients will weigh may have life-extending potential. Until now, there has been little understanding of the factors that patients take into consideration when they decide to pursue new treatment options that offer modest life extension.

In this study, we sought to identify key components of QOL and social support in determining therapeutic decision making and the overall value of life extension, in patients with NSCLC. Our first objective was to understand the social and emotional experience of living with

NSCLC, and to identify the needs of and sources of distress for these patients that might be used to inform the development of distress-screening tools for them. A second objective was to understand the motivating factors that patients take into consideration when they are asked to make trade-offs in considering potential life-extending treatment options.

Methods

Patients were eligible for this study if they were 18 years of age or older, spoke English, and had a diagnosis of NSCLC, irrespective of stage. Patients were recruited from 2 cancer advocacy and patient education/support organizations. All patients provided written informed consent.

To explore the full range of symptoms that patients considered important to QOL, as well as the value of life extension relative to QOL, we took a grounded theory approach.²¹ Focus groups were used as the primary means of eliciting the breadth and depth of perspectives of patients living with NSCLC. The goal of the focus group was to promote self-disclosure among participants. We subsequently conducted one-on-one telephone interviews to provide targeted and in-depth understanding of the themes explored in the focus groups

After patients had completed a brief demographic survey, we conducted 3 semistructured focus groups ($n = 16$) and telephone interviews ($n = 15$) with eligible participants ($N = 31$). In focus groups, trained moderators used a nominal group technique to ensure uniform participation from all patients and to elicit symptoms that patients considered most important.²² In subsequent interviews, patients were encouraged to name several important symptoms and then explain the significance of each. The focus groups and interviews were initiated with a simple prompt that asked participants to describe, in 1 or 2 words, a symptom related to their NSCLC that had affected their life, followed by a prompt asking which symptom most affected their life, and how. A trade-off format assessed the value of life extension relative to QOL. Patients were asked to consider an experimental (add-on) treatment that had been shown to increase lifespan by up to 3 months, on average. They were told that without this treatment, they may have about 7 to 8 months to live, on average, and that with this treatment they might have about 10 to 11 months to live, on average. Patients were then asked what factors they would take into consideration to make a decision.

Focus groups and interviews were moderated by 3 PhD-level and 1 master's-level researchers who were trained in qualitative methodology and had extensive experience in group and individual interviewing. Focus groups and interviews were digitally recorded and transcribed. Identifying information was redacted from all transcripts, which were then entered into NVivo 8 software for the coding and man-

agement of qualitative data. Two master-level researchers reviewed each transcript, coding for themes as they emerged from the data. Emergent themes from the first 2 transcripts were identified and entered into a codebook. Using the method of constant comparison, the codes from these first 2 transcripts were compared against themes found in subsequent transcripts; older themes and their representative codes were refined and organized into larger concepts, and newly emergent themes were entered into the codebook. As we reached thematic saturation (ie, no new themes emerged), we coded the remaining transcripts selectively for core concepts. Two coders applied this process to all 18 transcripts (from 15 interviews and 3 focus groups).

Results

Demographics

The patients' mean age was 61.6 years, 67.7% were women, 77.4% were white, 61.3% were not employed or were retired, 58.1% were living with a spouse/other, 93.5% had health insurance, and 48.4% had stage III/IV NSCLC. A summary of patient characteristics may be found in Table 1.

Symptoms findings

Although the medical definition of symptom is "experienced sign of disease," and "symptom" is typically associated with pain or debility, patients in the study conceptualized "symptom" differently. For patients, "symptom" corresponded to any alteration in one's lived experience due to disease. Thus patients considered any change in baseline emotional or physical experience, such as level of happiness or pain level, due to NSCLC, to be a symptom of NSCLC, regardless of whether that change was negative or positive.

The frequency distribution of emotional and physical symptoms is provided in Table 2. Of all 31 patients who participated in nominal focus group and interview elicitation, 68% (21 of 31) cited emotions and attitudinal orientation in response to the question, "What NSCLC symptoms have most affected your life?" Subsequently, 23 patients (all 16 in focus groups plus 7 in interviews prior to thematic saturation) were asked about specific emotional and physical symptoms; their leading emotions and attitudes included fear (31%), anxiety (23%), depression (7%), feeling defeated (7%), and loneliness (7%). Their key physical symptoms were respiratory complaints (53%) and fatigue (20%). Their key symptoms and concerns had changed over time, as 74% of patients reported shock and fear at diagnosis, and 55% felt fear or loneliness during the beginning of therapy.

I definitely felt lonely. I felt isolated.

—Interview 10

So I went on the rollercoaster ride ... and I had very toxic chemo. ... And it was just a very scary time for me.

—Interview 9

TABLE 1 Patient characteristics

Characteristic	Percentage of patients (N = 31)
Age	
Median, 63 y; Mean, 61.6 y (range, 36-78 y)	
Sex	
Female	67.7
Male	32.3
Education^a	
At least some college	96.9
Bachelor's degree or higher	64.6
Race	
White	77.4
African-American	9.7
Asian-American	6.5
Multi-racial	6.4
Community type	
Suburban	58.1
Urban	29.0
Other	12.9
Employment status	
Not employed, including retired	61.3
Full time (> 30 hrs/wk)	25.8
Part time (≥ 30 hrs/wk)	12.9
Total household income (\$)	
Less than 20,000	6.5
20,000 to 39,999	12.9
40,000 to 59,999	29.0
60,000 to 79,999	6.5
80,000 to 99,999	12.9
100,000 or greater	25.8
Don't know	6.4
Relationship status	
Married/living as married	51.6
Divorced	32.3
Widowed	9.7
Single/never married	3.2
Other	3.2
Current living situation^a	
Living with spouse/significant other	58.1
Living alone	25.8
Living with children aged < 18 years	22.6
Type of health insurance plan (\$)^a	
Medicare	51.6
Employer	38.7
Private	12.9
State-run	6.5
None	6.5
Histology	
Did not know/unknown	66.7
Nonsquamous	33.3
Past treatment^a	
Chemotherapy	80.6
Surgery	67.7
Radiation	61.3
Biologic therapy	22.6

^aRespondents may have included themselves in more than 1 category.

TABLE 2 Frequency of reporting specific symptoms in influencing quality of life^a

Symptom	Patients reporting symptom category and specific symptom (N = 23)	Patients reporting specific symptom within symptom categories, %	Patients reporting specific symptom in total assessed for specific symptoms, %
Physical (n = 15)			
Respiratory (wheezing, shortness of breath, coughing, blocked airways)	8	53.3	34.8
Fatigue (exhaustion, tired, feeling physically worn)	3	20.0	13.0
Nausea	2	13.3	8.7
Memory problems	1	6.7	4.3
Neuropathy	1	6.7	4.3
Emotional (n = 13)			
Fear (fear, scared, scary)	4	30.7	17.4
Anxiety (anxiety, increased heart rate)	3	23.1	13.0
Depression	1	7.7	4.3
Feeling defeated	1	7.7	4.3
Loneliness	1	7.7	4.3
Feeling hopeless	1	7.7	4.3
Positive change in faith	1	7.7	4.3
Positive change in attitude	1	7.7	4.3

^aDistribution of specific symptoms is reported for all patients until thematic saturation was reached. This included 16 patients from the 3 focus groups, plus 7 of 15 patients from the phone interviews.

Reports of shock at diagnosis were most common among NSCLC patients who had never smoked. Patients who had successfully connected with other NSCLC patients (peers), support groups, and/or community members (including family, friends, neighbors, and coworkers) reported a positive shift in feelings (52%) as they continued therapy or moved into a posttherapy phase.

There's somewhere, we'll say midpoint of the journey ... it started to be hope that I was going to survive this thing. ... God comforts us so that we can go and comfort others. ... I'm a caregiver at my church. So ... that's a cool place to be. -Interview 1

In addition, 26% of patients reported feeling confused and isolated during treatment because of information gaps.

But you know, going into what you said how I was treated at that time and everything, I was alone; there was no information about lung cancer out there. -Interview 8

Financially, 23% of patients reported being adversely impacted by copayments, 36% by unexpected gaps in coverage, and 39% by other bills; in all, 52% accepted help from any/all sources. The financial impact of NSCLC played into emotions of distress, and for those

who accepted financial help from unexpected sources gratitude.

Oh, we've been very fortunate. The company that my wife worked for at the time ... when they had found out what happened ... they said, "What we'd like to do is, we would like to cover the first \$5,000 of your treatment." And in between my blubbling and sniffing and ... not knowing what to say, I'm like, "Is there any way I could just write a letter and say thanks?" And they said they didn't do it for that. They don't care about a thank you. They just want to help. ... Without them, I wouldn't have made it. -Interview 2

Life extension vs QOL trade-off findings

To understand how patients value trade-offs between the length and quality of life, we examined their conceptualizations of QOL. In all, 4 interdependent yet distinct domains of QOL emerged from the data. We classified these 4 domains as "somatic" (defined as lack of physical pain and discomfort), "functional" (having mobility and the ability to physically perform to personal and social expectations), "relational" enjoyment and/or appropriate performance of social roles and interpersonal relationships, including at work), and "emotional" (emotional experience, such as happiness or sadness, deriving from satisfaction/dissatisfaction with lived experience). Table 3 provides representa-

tive excerpts from the transcripts indicating how patients perceived the trade-off between additional longevity and QOL in terms of each domain.

Although emotions played a strong role in patient descriptions of their lived experience of living with NSCLC, they receded in importance when patients were asked to make value trade-offs between life extension and QOL with regard to life-extending therapy. The most important factor driving decision making regarding a hypothetical treatment that might offer a 3-month life extension was the somatic domain (84%), followed by the functional (32%), relational (23%), and emotional (10%) domains. Yet across the majority of the focus groups and interviews, patients spontaneously related how NSCLC had positively and negatively impacted their relational and emotional QOL.

Discussion

The primary objective of this study was to identify key components of QOL and social support that would help determine therapeutic decision making and overall value of life extension in patients with NSCLC. Given the heterogeneity of expected patient experiences, we used a grounded theory approach to inductively develop critical concepts as they emerged from the patients' own words.^{21,23,24} To ensure that these qualitative processes captured the full range of patient experiences related to the variables of interest, we confirmed that the sample size was adequate to achieve thematic saturation (ie, no new themes continued to emerge in the final set of interviews).^{25,26} Two researchers coded the transcripts. Inter-coder reliability was high.

During nominal group and interview elicitation, we found that a majority (68%) of patients cited emotions and attitudinal orientation in response to the question, "What NSCLC symptoms have most affected your life," indicating that patients conceptualized emotions and attitudinal orientation as symptoms of NSCLC. Some 53% of patients also cited physical respiratory symptoms (eg, wheezing, coughing, shortness of breath, blocked airways) as having an impact on their lives. One possible explanation for this finding in our sample highlights the association between physical respiratory symptoms and the anxiety and worry that are triggered by those. Respiratory issues are a hallmark symptom associated with NSCLC,^{27,28} and anxiety and worry often accompany respiratory symptoms. Because respiratory difficulties often cause feelings of anxiety and worry, differentiating between the emotional and physical symptomatology of these issues can be difficult. In general, the increased likelihood of respiratory issues in lung cancer may partially explain reports of heightened distress in lung cancer patients, compared with other cancer groups.⁴

Clearly, the link between lung cancer and anxiety makes it more difficult to identify the source of distress in lung cancer patients. However, identifying and treating this distress are critical to avoid the negative patient outcomes that are associated with untreated distress.^{5,6} When these patients are screened for distress, it is important to assess the extent to which the physical symptoms related to respiratory burden may be triggering anxiety. Those with anxiety primarily resulting from respiratory issues could be managed and treated accordingly to minimize the experienced distress. Similarly, those with a history of anxiety may be

TABLE 3 Frequency and characterization of quality of life domains in influencing treatment decisions

QOL domain	Description	Representative excerpt	Sample using domain in making treatment decisions, % (N=31)
Somatic	Lack of physical pain and discomfort	If I got to be sick and go through treatment all over again and to get [only] 3 months, who would want to suffer for 3 months? Not me. Focus group 2, participant 1	84
Functional	Mobility and ability to perform physically to personal and social expectations	If it came to a point where I could not stand upright and walk and eat and function and smile and provide loving care to my friends and family and just function in society, that's where I'd draw the line. Interview 13	32
Relational	Enjoyment and/or appropriate performance of social roles and inter-personal relationships, including work	Am I able to communicate with my family? You know, am I all there? Or am I just laying there, a big lump of what used to be me? Interview 1	23
Emotional	Emotional experience deriving from satisfaction/ dissatisfaction with lived experience	I'm not going to go [die] like my mother. Certainly we know a lot more now than we did when she passed away, but it's a big scare.a ... Focus group 2, participant 2	10

QoL, quality of life.

^aThe participant was suggesting that in general, she was not going to die like her mother did. She wanted to be more informed, less frightened, and more empowered overall than her mother was.

managed with a combination of evidence-based treatments, including cognitive behavioral therapy and/or pharmacological approaches. In general, knowing the extent to which medical variables can account for psychological distress is important because it can help predict those patients at risk for greatest distress,²⁹ and suitably direct treatment modalities. Lung cancer patients in particular should be followed with a thorough consideration of whether management of respiratory issues may lower distress, or whether distress may be associated with other social and emotional factors (eg, disruptions in home life or finances).

The timing of emotions is worthy of note. Shock and fear dominated participants' emotional experience at diagnosis. Over time, however, more than half the patients connected successfully with support groups, other lung cancer patients, neighbors, and coworkers, and they reported a positive shift in feelings, with many patients using positive words such as hopeful and confident when describing their current emotional experience. This is perhaps not surprising; other evidence has shown that a lack of social support can be detrimental to psychological well-being and QOL among breast cancer survivors.³⁰ Of course, successful treatment might also have a role in shifting attitudes.

Our study is the first patient focus group/interview study to directly assess the impact of financial factors including the effect of copayments and other medical bills, as well as sources of financial support, both institutional and personal on cancer patients' well-being. About one-fourth to one-third of patients reported being affected by copayments, subsequent medical bills, and unexpected gaps in coverage, and more than half of them acknowledged help from any and all sources. The reported financial distress in our study is consistent with findings from a large database study using the Surveillance, Epidemiology, and End-Results registry, which showed that among all malignancies, lung cancer had the highest rate (~8%) of devastating financial consequences, such as personal bankruptcy, for patients.³¹

Despite the prominent role of emotional factors in patient descriptions of the lived experience of NSCLC, they receded in importance when patients were asked to make value trade-offs between life extension and QOL with regard to life-extending therapy. The most important factor driving decision making regarding a hypothetical treatment offering a 3-month life extension was the somatic domain (84%), followed by functional (32%), relational (23%), and emotional (10%) factors. Interestingly, the domains of QOL that emerged in this study are consistent with those identified during the development and validation of the Functional Assessment of Cancer Therapy scale (FACT-G).³²

Clearly, somatic QOL concerns (ahead of functional, emotional and relational QOL) were the dominant driver of therapeutic decision making in our hypothetical scenario. As life-extending drugs become more readily avail-

able, health care professionals should recognize that the management of side effects and physical symptoms is of the utmost importance to the patient. Health care professionals should be explicit in explaining somatic symptoms and the side effects of various treatment options. Future studies should address the impact of cost and patients' willingness to pay on the relationship between somatic concerns and end of life/lifeextension decision making.

The current study did not directly examine the extent to which participants' psychosocial experiences with NSCLC differed as a function of their current cancer stage. We did, however, note that the emotions reported by participants differed across the cancer journey (at diagnosis, during treatment, and in survivorship) and we suspect that similar differences may have emerged if we had examined the role of stage as an independent variable. Future studies should explore this relationship to ensure that psychosocial needs are adequately understood for all patients living with NSCLC.

It is important to acknowledge the limitations of this study. Participants were recruited from 2 cancer advocacy and patient education/support organizations. Thus, the individuals who participated in this study were likely to have received some education or support from 1 of these 2 organizations. Results may therefore reflect bias toward individuals who seek social support, and may be less representative of individuals who do not seek psychosocial cancer support from community-based organizations. Additionally, this study is limited in that the overwhelming majority (94%) of participants reported having health insurance. Participants lacking insurance might have been more likely to consider financial variables when making treatment decisions in the context of modest life extension. Finally, all but 1 of the patients interviewed had at least some college education, and fewer than 20% had a household income of less than \$40,000 yearly, putting this group in a higher socioeconomic class than that of average lung cancer patients. Therefore, results are not automatically generalizable to participants who are uninsured or to those who have a lower socioeconomic status.

Conclusions

This study makes an important contribution in understanding the psychosocial experience of living with NSCLC, and corroborates previous findings that individuals living with NSCLC experience a significant amount of interdependent emotional and somatic distress. These findings provide support for recent recommendations regarding the use of psychosocial distress screening and referral to improve the quality of cancer survivorship.³³ The need for screening is especially acute at diagnosis and during initial therapy, given the high rate of shock, fear, and perceived loneliness that was reported in this study. Our findings suggest that financial distress screening should also be incorporated to

current distress tools, and that appropriate financial assistance referrals, such as copayment assistance programs, should be provided. Furthermore, our results provide insight into the trade-offs and factors that individuals with NSCLC consider when they make treatment decisions that offer modest life extension. These identified factors should inform health care professionals about ways to talk with their patients about such decisions. As NSCLC treatments improve and patients live longer, it is increasingly important to develop interventions to help patients live fuller lives and to support them in the process of shared decision making.

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