Cancer-related distress and unmet needs among those with metastatic and non-metastatic non-small cell lung cancer: Findings from the Cancer Experience Registry

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Abstract #539

Background

Individuals with non-small cell lung cancer (NSCLC) are susceptible to distress across multiple life domains.

This study aims to describe how individuals living with metastatic or non-metastatic NSCLC characterize cancer-related distress, and to identify socio-demographic and clinical factors predicting distress.

Methods

- From Feb 2015-Nov 2023, 279 US adults with a history of NSCLC participated in the **Cancer Experience Registry®**, an online survey about the multidimensional impact of cancer.
- The patients ranged in age from 35 to 87 years old (M = 64, SD = 11), were 88% non-Hispanic White, and 68% identified as women.
- **Annual income:** 31% earned <$40K, 23% earned between $40K and $79,999, and 19% earned $80K+.
- **Employment:** Over half were retired (52%), while 24% were unemployed due to disability, and 23% were employed either full- or part-time.
- **Clinical History:** Time since diagnosis averaged 5 years (SD = 7), with 28% diagnosed within the past year, 37% between 2–5 years ago, and 32% more than 5 years ago. Over half of the participants (56%) reported having metastatic NSCLC.
- **CancerSupportSource™ (CSS)** is a validated 25-item tool asking patients about distress across 5 domains (Table 1). Items are scored 0 (*not at all*) to 4 (*very much*) concerned.
- Multiple linear regression analysis was used to assess the relationships between CSS domain Mean scores, demographic variables (age, gender, income, employment status), and clinical factors (time since diagnosis, metastatic status, treatment).

NSCLC patients report substantial distress related to future uncertainty, fatigue, and physical activity, regardless of metastatic status.

*While individuals with **metastatic** NSCLC expressed more concern about loved ones, those with **non-metastatic** NSCLC reported more distress around daily mobility.*

Results

Table 1. Top cancer-related distress scores by metastatic status

Cancer Support Source (CSS) Domains	M	SD	Med	Top concerns for all (Metastatic / Not)	Differences* by metastatic status (Metastatic / Not)
Body Image & Health Lifestyle (BHL)	1.26	0.9	1	**Exercising and being physically active** is a top concern for all (M=1.5 / M=1.7)	N/A
Emotional Well-being (EWB)	1.23	0.9	1.1	**Worrying about the future** is a top concern for all (M=1.8 / M=1.7)	**Worry about family and friends** higher for metastatic (M=1.5 / M=1.1)
Relationships & Intimacy (REL)	1.20	1.1	1	No items in top concerns overall	**Problems with spouse/partner** higher for metastatic (M=0.8 / M=0.4)
Symptom Burden & Impact (SYM)	1.07	0.8	0.9	**Feeling too tired** to do things you want or need to do is a top concern for all (M=1.6 / M=1.7)	**Moving around** (walking, climbing stairs, etc.) higher for non-metastatic (M=1.3/ M=1.6)
Healthcare Team Communication (HTC)	0.83	1	0.5	**Communicating with doctors** among the lowest concerns for all (M=0.7 / M=0.7)	N/A

*CSS includes 25 items scored on a 5-point scale from 0 (not all all) to 4 (very much) in response to the stem: Today, how concerned are you about… These items are grouped into the 5 domains, shown above. Mean scores are calculated by domain and used as outcome variables in regression analysis. *Significant group differences based on independent samples t-tests (p<.05). M=Mean; SD=Standard Deviation; Med=Median*

In multivariable analysis:

- Younger age was associated with higher distress in three domains (BHL, EWB, REL) and higher distress overall.
- Women expressed higher distress in three domains (BHL, EWB, SYM) and higher distress overall.
- Those employed or retired, rather than unemployed due to disability, had lower distress in all domains.
- Clinical history variables included in the models—time since diagnosis and metastatic status—were not significant predictors of distress in multivariable models.

Conclusions & Future Directions

- Providers should prioritize support for coping with uncertainty, managing fatigue, and maintaining physical activity, which are core concerns, regardless of metastatic status.
- Findings suggest that tailored support may also be beneficial, with a focus on emotional and relational support for those with metastatic NSCLC, and assistance with mobility and daily tasks for those with non-metastatic NSCLC.
- This sample was predominantly non-Hispanic White and women, which may limit the generalizability of findings to broader populations with NSCLC. Moreover, other potentially relevant clinical factors were not collected and should be considered when determining optimal support for patients.