“New normal” vs. “Getting back to life”: How Patients with Metastatic and Non-Metastatic NSCLC Perceive and Evaluate their Quality of Life

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Abstract PP01.51

Background

People with non-small cell lung cancer (NSCLC) often experience significant symptom burden, poor quality of life (QoL), and psychosocial distress.

This study assessed the nature and extent of symptom burden among patients with metastatic and non-metastatic NSCLC and the factors associated with poor QoL to identify unmet needs and inform psychosocial interventions

Methods

We conducted a mixed-methods study involving retrospective quantitative analysis of **279 patients’ survey responses** in the Cancer Experience Registry® (CER) and qualitative analysis of **25 in-depth interviews with patients** with NSCLC.

279 patients’ self-reported QoL → Interview study design → 25 in-depth patient interviews

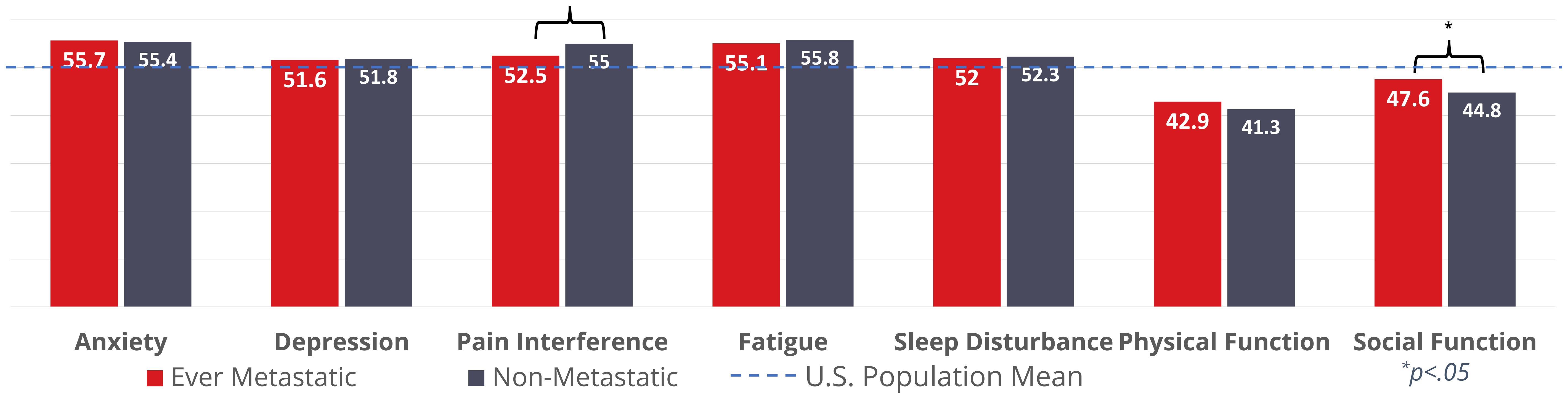
- **Quantitative analysis**: Descriptive statistics were used to assess differences in symptom burden by metastatic status, line of therapy, and treatment experience using PROMIS 29.v2 subscales among patients with metastatic (*n*=154) and non-metastatic (*n*=120) NSCLC.
  - Quantitative results showed that patients with non-metastatic disease reported more intense **pain interference** and **poorer social function** than patients with metastatic disease.
  - *Hypothesis*: Patients’ perceptions of non-metastatic disease as “**curable**” compared to metastatic disease as “**chronic**” impacted how they rated their QoL
- **Qualitative analysis**: We conducted semi-structured interviews with patients with NSCLC (18 w/ metastatic and 7 with non-metastatic disease) to contextualize quantitative findings and assess this hypothesis by exploring patients’ treatment experiences, symptom burden, psychosocial distress, and unmet needs.

Patients with **non-metastatic** disease expected to regain their pre-diagnosis QoL – or “**get back to life**” – after treatment. When symptom burden persisted after treatment, patients rated their QoL as more limited compared to those with metastatic disease.

Those with **metastatic disease** perceived their diagnosis as life-changing and reduced QoL as their “**new normal**,” rating their symptom burden as less prohibitive.

Results: Differences in quality of life by metastatic status

Figure 1. PROMIS-29 symptom burden and functioning scores by metastatic status



Based on independent sample t-test results of 279 U.S. adults with NSCLC from the CER, including 120 patients with non-metastatic and 154 with metastatic NSCLC. Participants with non-metastatic NSCLC reported significantly more pain interference (M=55.0; SD=11.6) and worse social function (M=44.8; SD=10.2) than participants with metastatic NSCLC (M=52.5; SD=10.5), t(276)=1.8; p=.03); (M=47.6; SD=9.6), t(272)=-2.3; p=.01).

Mild-to-severe anxiety (58%) and fatigue (57%) were common among patients surveyed.

However, patients with non-metastatic NSCLC reported **more pain** and **worse social function** than those with metastatic NSCLC.

During interviews, most patients with metastatic disease (15/18) described their limited QoL as “new normal,” while most with non-metastatic NSCLC (6/7) were frustrated that their poor QoL persisted even after completing treatment.

“It’s frustrating”

“I’m much slower in my running than what I used to be… **I still can run and still climb and stuff, but I can’t do it as well as I did, so I get frustrated with that**… There’s a race in Colorado in June, I can’t run it right now… There was a lot of stuff that I should have been able to do that used to be super easy, but I couldn’t do it, and that was frustrating… ” (*Julie, 52 years-old, Stage II*)

“I call it my new normal”

“The **fatigue, I call it my new normal. What helps with the fatigue is realizing I can't do things in a row anymore**. Yesterday was good, because for 3 hours I didn't have fatigue, and then I noticed it came back. And I can't do anything, but I have to - in my mind, I have to do things, but now I have to stop and rest.” - (*Linda, 82 years-old, Stage IV*)

Conclusions & Future Directions

- Although intense fatigue and anxiety were common among patients and negatively impacted their QoL, most patients with non-metastatic NSCLC rated their QoL as worse than patients with metastatic NSCLC.
  - Patients’ perceptions of and experiences with NSCLC seem to impact their evaluations of QoL.
- Given patients’ intense symptom burden and anxiety about reduced QoL, it is essential to increase access to tailored evidence-based interventions, such as acceptance and commitment therapy to manage expectations about symptom burden for patients with non-metastatic NSCLC, and social support for patients with metastatic NSCLC.
- Future studies should examine how patients’ QoL differs by gender and race/ethnicity to identify disparities and develop tailored interventions to improve equity in patient care, along with tailored interventions for people receiving different types of treatment.

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