CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

Psychosocial Distress and Coping Strategies among People Diagnosed with Metastatic and Non-metastatic Non-small Cell Lung Cancer

Abigail Newell, PhD[1], Erica Fortune, PhD[1], Maria B. Gonzalo,MS[1], Inderjit K. Dhillon, PhD[2], Nandita Kachru, PhD[2], and Cosmina Hogea, PhD[2]

[1]Cancer Support Community, Washington, DC; [2]Gilead, Foster City, CA

BACKGROUND

Symptom burden and psychosocial distress can hamper quality of life (QoL) for people with non-small cell lung cancer (NSCLC). Previous research suggests that people with metastatic NSCLC have worse symptom burden and QoL than those with non-metastatic disease. However, few studies have directly compared the experiences of patients with metastatic and non-metastatic NSCLC with regards to symptom burden and QoL.

AIMS

The study aimed to explore the experiences of symptom burden, distress, and quality of life (QoL) among individuals with metastatic and non-metastatic NSCLC.

METHODS

- We conducted semi-structured interviews with 25 adults with NSCLC who received treatment in the past 24 months.
- We oversampled those with metastatic disease and maximized variation in line of therapy and treatment history to compare experiences by clinical characteristics.
- Interviews discussed patients' treatment history and experiences, symptom burden, impact on daily life, sources of distress, coping strategies, and unmet needs.
- De-identified transcripts were analyzed in *NVivo 14* using an iterative deductive-inductive coding approach, incorporating both study objectives and emergent themes from the data.

PARTICIPANTS

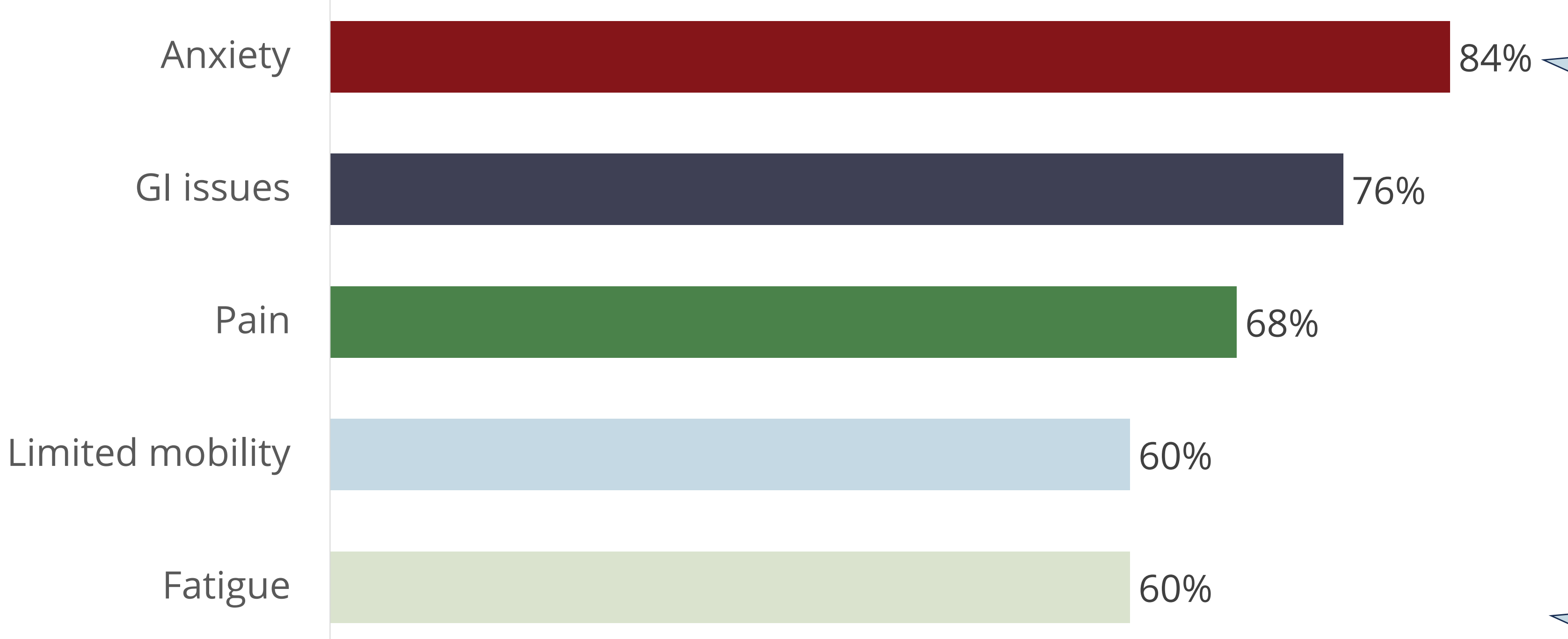
Demographic	*M* / %	Clinical	%
Age (mean years)	*M*=64.0	**Met. status**	
Gender		Never Met	28%
Woman	80%	Metastatic	72%
Man	20%	**Time since Dx**	
Race/ethnicity		1-2 years	28%
Asian / Asian American	8%	3-5 years	40%
Black / African American	4%	>5 years	32%
Hispanic or Latino	8%	**Line of therapy**	
White	80%	1L	46%
Education		2L +	64%
High school, GED, trade	12%	**Treatment***	
Some college / associate	28%	Chemotherapy	64%
Bachelor's degree	36%	Radiation	64%
Graduate degree	20%	Immunotherapy	60%
Prefer not to share	4%	Targeted therapy	52%
Employment status		Surgery	36%
Full or part-time	16%	Palliative care	20%
Unemployed, disability	28%	Clinical trial	8%
Retired	44%	Other	8%
Unemployed, other	12%		

*N=25; *treatment history includes participants who have ever received treatment type; categories are not mutually exclusive.*

RESULTS

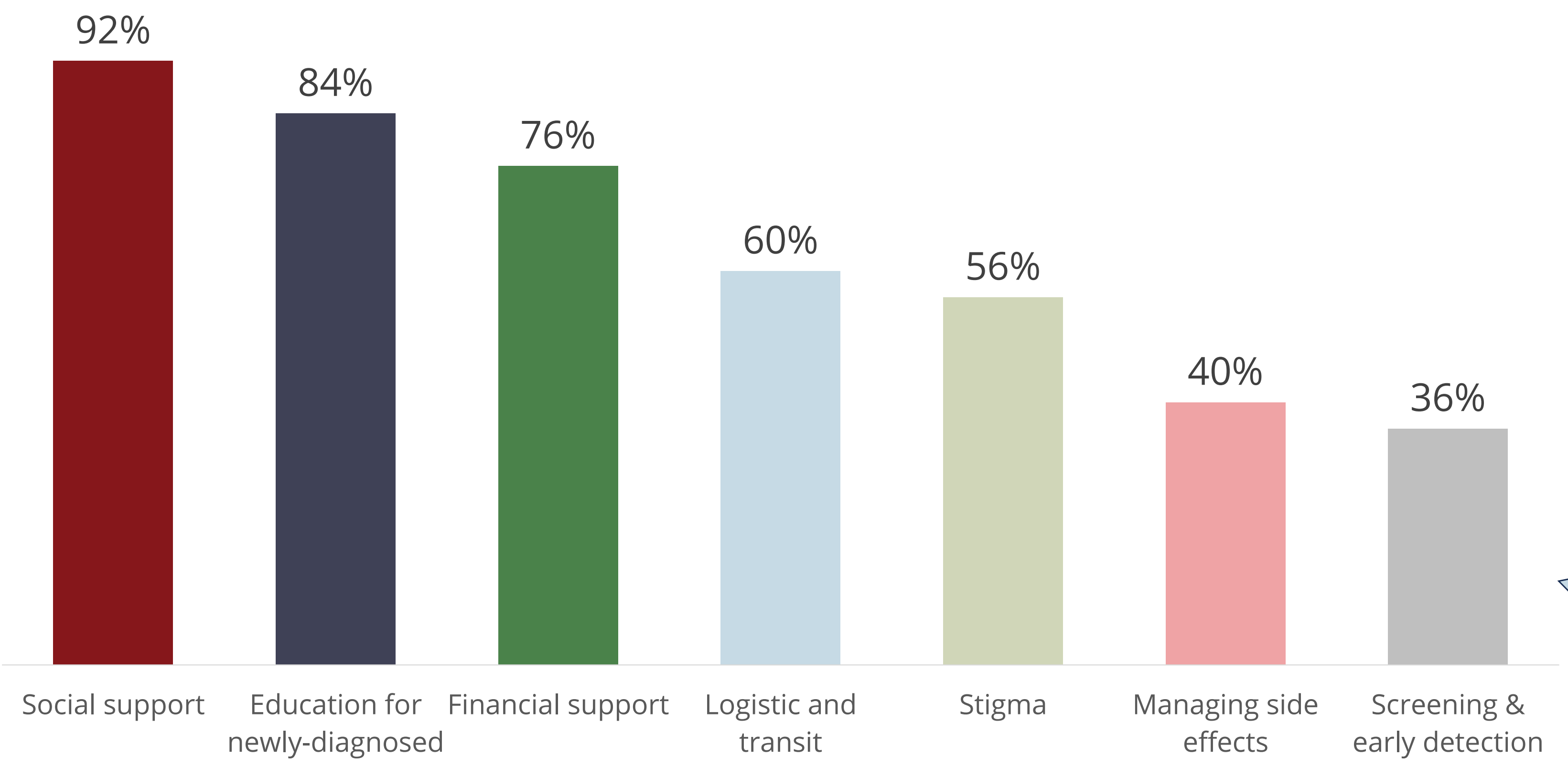
Patients with metastatic and non-metastatic NSCLC experienced intense symptom burden.

Table 1: Top symptoms among NSCLC patients



% of participants reporting symptom burden (n=25 participants)

Table 2: Top unmet needs among NSCLC patients



% of participants reporting symptom burden (n=25 participants)

Anxiety around recurrence

> *"This anxiety comes back to fear of – I want to make sure my kids are settled. I've even saved up money for my own funeral arrangements and everything, so it wouldn't be put on them… **To make sure my kids aren't burdened financially because that's my biggest worry**."*
>
> *(Susanne*, diagnosed with Stage IV NSCLC)*

Persistent fatigue

> *"The fatigue is pretty tough, so that and the neuropathy, definitely affects my life… **Cancer has really done a number on me. I aged overnight**. I still felt pretty young at 60, and I did kind of right up until I got this.. And wow, this really, really changed me."*
>
> *(Brenda, diagnosed with Stage IV NSCLC)*

Lack of education for newly-diagnosed

> *"I'm much more educated now than when I was [first diagnosed]. **At that point, my world was still in a blender**. The surgery was offered up as an option, and my thought was, "Get it out." At the time, I really didn't know about [targeted therapy]. **Had I known about the [targeted therapy], would I have opted to leave the main tumor?**…I feel like I wasn't given options that I wish I'd known beforehand…"*
>
> *(Kathleen, diagnosed with Stage IV NSCLC)*

**Pseudonyms are used throughout to protect participants' identities*

Most (84%) patients reported anxiety around fear of recurrence or progression, but patients with metastatic and non-metastatic NSCLC coped with the anxiety of recurrence or progression differently.

Metastatic

Most (**83%**) patients with metastatic NSCLC coped with fear of recurrence by accepting reduced QoL as their "**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 couldn't do anything. **In my mind, I have to do things, but now I have to stop and rest**."*
>
> *(Linda, diagnosed with Stage IV NSCLC)*

Non-metastatic

Most (78%) patients with non-metastatic disease struggled to cope with anxiety because they expected to be "**cured.**"

> *"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 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, diagnosed with Stage II NSCLC)*

CONCLUSIONS AND IMPLICATIONS

- People with NSCLC experience intense symptom burden, including anxiety, GI issues, pain, and fatigue, that negatively impacts their quality of life.
- Anxiety about recurrence and progression is common, even among those with non-metastatic disease who struggled to cope with persistent symptom burden after expecting to be "cured," compared to those with metastatic disease who coped with anxiety by framing reduced QoL as their "new normal."
- Increased access to psychosocial support for all NSCLC patients, especially **education for those recently diagnosed** and **long-term social and emotional support**, is critical to mitigate anxiety and symptom burden and improve quality of life.
- Future studies should examine patients' perceptions of treatment outcomes and coping strategies among representative samples given the limited racial and gender diversity of this sample.

American Psychosocial Oncology Society (APOS) 2026 Annual Conference: March 18-20, 2026, New Orleans, LA

Funding for this study was provided by Gilead Sciences, Inc.

Contact: Abigail Newell, PhD: anewell@cancersupportcommunity.org