



GAPS IN SUPPORTIVE AND SURVIVORSHIP CARE FOR LUNG CANCER PATIENTS

Tara Perloff, Jennifer C. King PhD, Maureen Rigney MSW LICSW

INTRODUCTION

Clinical guidelines increasingly recommend an expansion of multidisciplinary care for oncology patients to include supportive and survivorship care. Despite recommendations and research showing the need for such services, lung cancer patients may not have access to this type of care due to implementation challenges among health care delivery systems.

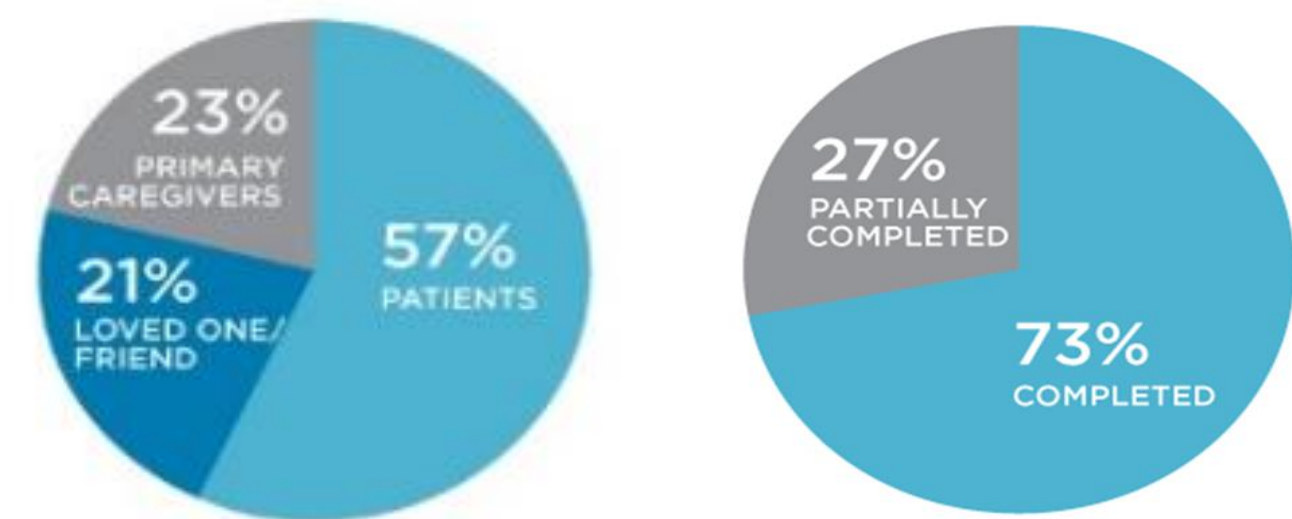
Our study goal was to assess the availability of treatment and care planning from the perspectives of lung cancer patients and their caregivers.

METHODOLOGY

A "Lung Cancer Community Needs Assessment" anonymous online survey was developed by Lung Cancer Alliance (LCA) and distributed to lung cancer patients and caregivers from 11/9/2015 to 2/8/2016. The survey was promoted electronically through social media (Twitter and Facebook) and electronic newsletters. The survey URL was also posted twice to the Inspire patient community. In addition, 15 long-term survivors known to be without internet access were called by a LCA staff member and 10 of them completed the survey by phone.

The survey assessed the patient's care team, values-based discussions in care planning, discussions regarding palliative care, and survivorship care planning. Demographic information was collected to determine if patterns of care correlated with geographical or socioeconomic factors.

- 820 people responded, including 471 patients/survivors and 349 caregivers, 181 of whom were the primary caregiver.
- The overall completion rate was 72.6%.



DEMOGRAPHICS

The following demographic data reflects the 471 survey respondents who identified as patients. Demographic questions were optional and the number of respondents is indicated. 357 patients (87%) reported having Non-Small Cell Lung Cancer (NSCLC).

Sex	(n=407)	
Male	68	16.7%
Female	339	83.3%
Race	(n=365)	
White	342	93.7%
Black/African American	7	1.9%
American Indian/Alaskan Native	2	0.5%
Japanese	1	0.3%
Chinese	8	2.2%
Other Asian	2	0.5%
Other	3	0.8%
Ethnicity	(n=302)	
Hispanic/Latino	6	2.0%
Not Hispanic or Latino	296	98.0%
Residential Setting	(n=411)	
Rural	96	23.36%
Suburban	235	57.18%
Urban	80	19.46%
Household Income	(n=363)	
Less than \$20,000	27	7.4%
\$20,000 - \$39,999	41	11.3%
\$40,000 - \$59,999	74	20.4%
\$60,000 - \$79,999	53	14.6%
\$80,000 - \$99,999	50	13.8%
\$100,000 and over	118	32.5%

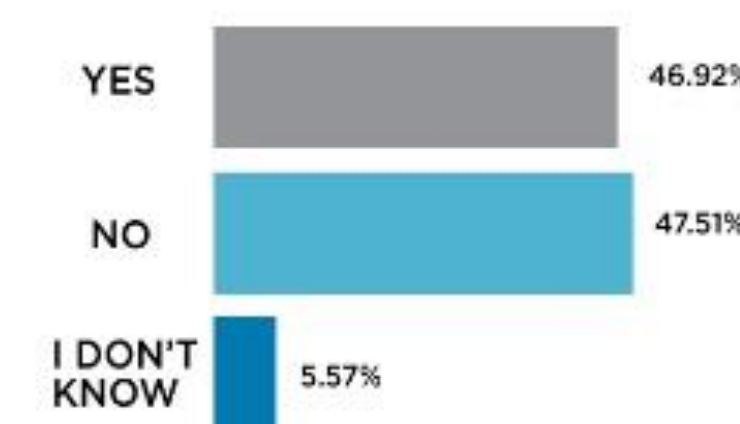
Caregiver-reported patient demographics represented a different population:

- 51% male, 48% female, 40-60 at diagnosis
- 91% white, 96% not Hispanic
- 34% never smoker, 41% former, 22% current smoker
- Cancers diagnosed later stage
- 55% said the patient they cared for is no longer alive

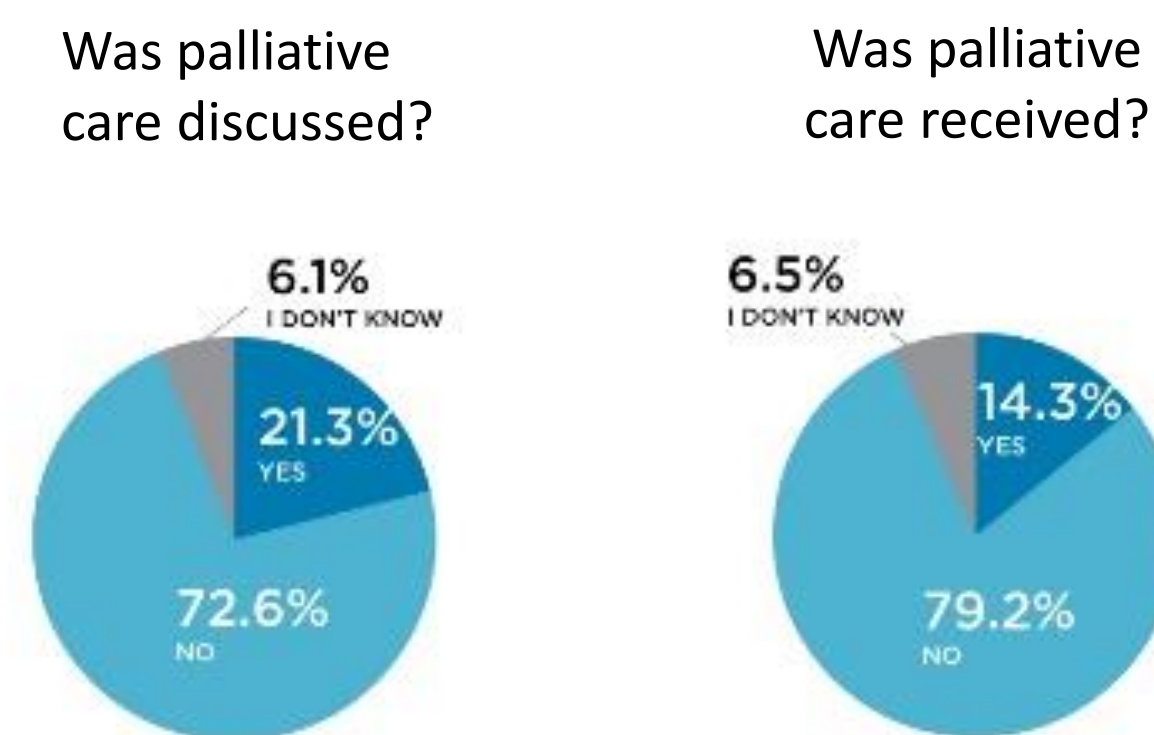
RESULTS

Less than 50% of patients reported having a conversation about their values and care goals with their treatment team before determining their treatment plan.

"Before starting treatment, did you have a discussion with your doctor/care team about your personal goals for your treatment and what you valued most? (n=341 patients)"



Only 26.9% of active patients had discussed palliative care and 20.13% reported receiving palliative care, despite data in lung cancer showing its potential survival benefit. (Temel et al, NEJM 2010). For all patients surveyed (n=376):

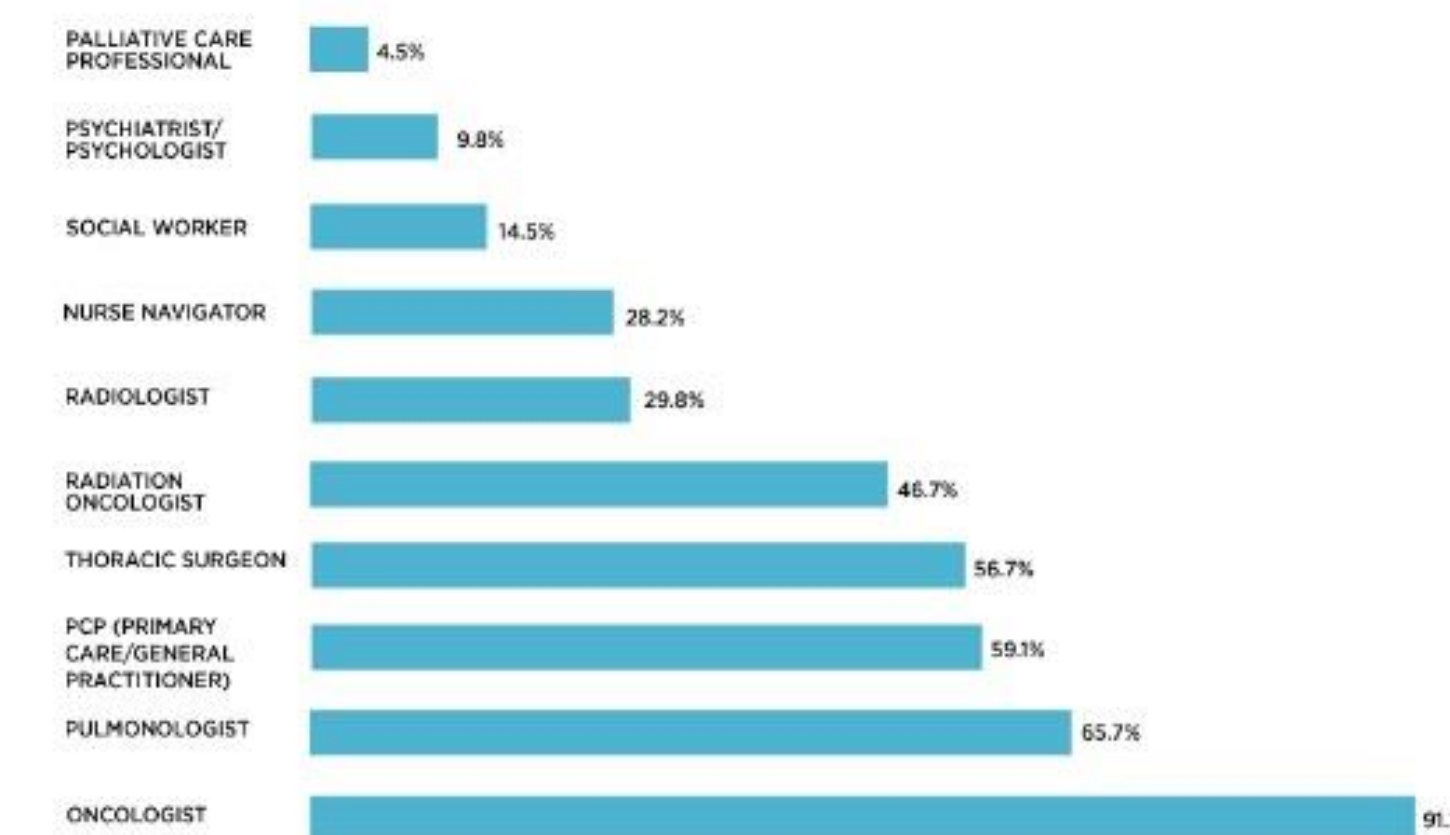


None of the patients (n=79) who were 5+ year survivors reported a palliative care professional being on their team at any point in their treatment or survivorship.

RESULTS

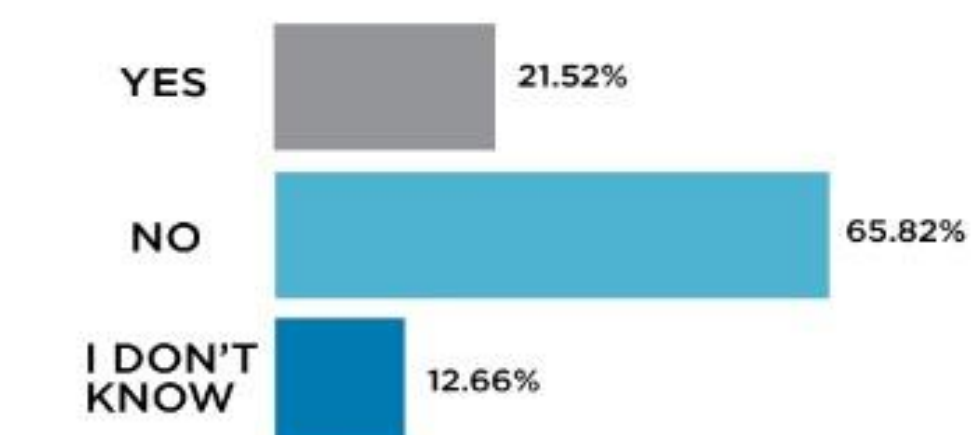
Less than 30% of patients reported a mental health professional, social worker, palliative care specialist, or nurse navigator as part of their care team.

Care team during active treatment (n=379):



Only 22% of patients and 15% of caregivers reported having a survivorship care plan of those who had completed treatment and survived more than 5 years beyond diagnosis.

"Did you/do you have a survivorship care plan? And if so, was it helpful (n= 79 patients who were >5 year survivors)?"



Was it helpful? 100% said Yes
n=11 patients who responded to open-ended question

INDIVIDUAL RESPONSES

"Please describe any needs that you had that you feel were not met when you were going through treatment (n= 221 patients and caregivers who responded to open-ended question)."



LIMITATIONS

The Needs Assessment was online and therefore does not represent the entirety of the lung cancer community. There was also poor ethnic and racial diversity in the survey population.

CONCLUSIONS

The majority of lung cancer patients and caregivers reported having not received palliative care, survivorship care plans, psychosocial support, or values-based discussions with their oncologist.

Respondents were technology enabled and health literate indicating that these problems could be more widespread in rural, lower socioeconomic areas where lung cancer is common. Addressing these problems in health care delivery could positively impact the survivorship of lung cancer patients and their families.

FUTURE RESEARCH

Future directions for this work should include:

- A broader study of a more fully representation population of the lung cancer community
- Implementation research around incorporation of survivorship care planning and palliative care
- Provider education on values-based care planning and incorporation of psychosocial support into multidisciplinary teams