BACKGROUND

The presence of lung cancer stigma is well documented in the scientific literature (Chapple et al. 2004; Chambers et al. 2012; Metlow et al. 2015) and has been shown to impact the care and treatment of lung cancer survivors (Tod et al. 2008; Carter-Harris et al. 2014).

In 2008, a large survey of over 200 patients, 200 oncologists, and 1000 members of the general population revealed that most participants felt that lung cancer was principally caused by external factors, that it was preventable, and that lung cancer patients were at least partly to blame for their illness (Weiss et al. 2014; Weiss et al. 2017).

We sought to understand whether perceptions in the three distinct groups have changed over the last decade with the advent of increasing lung cancer advocacy and a changing treatment paradigm.

METHODS

1001 members of the general public, 208 patients with lung cancer, and 205 oncologists who treat lung cancer patients were surveyed with the identical survey instrument from the 2008 survey. Five to fifteen additional questions were added at the end of the questionnaire including the strongest-loaded items from the validated Cataldo Lung Cancer Stigma Scale (Cataldo et al. 2011) for the patient participants. The survey was carried out by Russell Research by phone and online between June 6 and July 26, 2018 with the same methodology as the original 2008; Carter-Harris et al 2014).

RESULTS

Lung Cancer Awareness Has Increased in the Past Decade

- How do you think the amount of information about lung cancer in the media today compares to what you saw 10 years ago?
- 94% of general public report being familiar with lung cancer in 2018 vs 82.5% in 2008 (p<0.001)
- Familiarity with most cancers increased. Liver, brain, & lung were top three highest increases.
- Patients are increasing their use of advocacy groups (39% vs 18%, p<.0005)

Care for Those With Lung Cancer Is Improving

- When oncologists were asked about metastatic cancer types and if they had adequate treatment options to prolong patients' lives and halt disease:
  - Lung cancer: 52% “yes” vs 31% in 2008 (p<0.0005)
  - Breast cancer: 80% “yes” vs 85% in 2008 (NS)

Most patients reported satisfaction with both medical care (87%) and treatment options (71%).

Stigma Remains High

- Both the general public and oncologists who treat lung cancer were given statements and asked to respond to a 5-point agreement scale from agree completely to disagree completely. There was no improvement in either group compared to ten years ago in the percentage of people who felt lung cancer patients were stigmatized, treated differently, or blamed for their illness.

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Patients Are Experiencing More Stigma

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CONCLUSIONS

After a decade of research progress in lung cancer, these data show that lung cancer awareness has been considerably elevated.

Unfortunately, they indicate that the stigma surrounding the disease is pervasive. Interestingly, stigma was reported more frequently by the lung cancer patients and seems to be felt more acutely. This is perhaps due to increased awareness and empowerment around the disease.

CALL TO ACTION

“There is a unique opportunity to be proactive rather than reactive in this arena. Successfully addressing stigma is an important step in fulfilling the promise to reduce the burden of lung cancer.”

- Harmann, Ver Hoeve, Carter-Harris, Studts, and Ostroff (J Thorac Oncol. 2018 Aug;13(8):1062-1075.)