BACKGROUND

The presence of lung cancer stigma is well documented in the scientific literature (Chapple et al., 2004; Chambers et al., 2012; Marlow 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 primarily 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 study.

Statistical analysis was performed comparing 2008 and 2018 datasets using paired t-tests if normally distributed or Mann-Whitney U tests for continuous data and Chi-squared or Fisher’s exact test for categorical data.

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?

<table>
<thead>
<tr>
<th></th>
<th>2008</th>
<th>2018</th>
<th>p&lt;0.001</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Public</td>
<td>65</td>
<td>74</td>
<td>0.0005</td>
</tr>
<tr>
<td>Public Patients</td>
<td>65</td>
<td>76</td>
<td>0.0005</td>
</tr>
<tr>
<td>Oncologists</td>
<td>63</td>
<td>78</td>
<td>0.0005</td>
</tr>
</tbody>
</table>

- 94% of general public report being familiar with lung cancer in 2018 vs 82.5% in 2008 (p<.0001)
- 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:

<table>
<thead>
<tr>
<th></th>
<th>Lung cancer: 52% yes vs 31% in 2008 (p&lt;0.0005)</th>
<th>Breast cancer: 80% yes vs 75% in 2008 (NS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oncologists</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>General Public</td>
<td>Yes</td>
<td>Yes</td>
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</tbody>
</table>

Stigma Remains High

General Public

Lung cancer patients are at least partly to blame for their disease (63% vs 78% in 2008).

Lung cancer patients feel differently than other cancer patients (49% vs 63% in 2008).

Oncologists:

- There is stigma associated with lung cancer.
- There is less stigma associated with lung cancer if the patient never smoked.

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.

Patients Are Perceiving More Stigma

I feel there is a stigma associated with lung cancer.

I feel lung cancer patients are viewed or treated differently than other cancer patients.

I blame myself for developing lung cancer.

Struggling against stigma (stigmatized or non-stigmatized) had a significant impact on patients.

If you were treated differently, would you be more supportive of me if I had a different type of cancer?

Patients were also given statements and asked to respond to a 5-point agreement scale from agree completely to disagree completely. For most statements, more people felt stigmatized or blamed for their lung cancer compared to a decade ago. p values in red indicate statistically significant changes.

Patients were asked the following questions. The chart shows the percentage of respondents that answered “Yes” in each of the two surveys.

Do you feel that people with lung cancer are viewed or treated differently than people with other types of cancer by our society in general?

Do you feel that, you, personally, have been viewed or treated differently by our society in general?

Patients who agreed with the following statements are shown in the chart.

If you were treated differently, would you be more supportive of me if I had a different type of cancer?

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.

ACKNOWLEDGMENTS

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A special thanks to all the patients with lung cancer, oncologists who treat lung cancer, and members of the public who participated in the survey.

CONTACT

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FUTURE DIRECTIONS

Additional analyses of these datasets are ongoing. Current work includes analysis of subgroups within each survey population. Additionally, patient responses are being correlated to the validated Cataldo Lung Cancer Stigma Scale.

CALL TO ACTION

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

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