Stigma in Cancer Survivors with a Smoking History: What Cancer Coalitions Need to Know

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Faculty Disclosure

• I have no conflicts of interest to report.

• My presentation addresses lung cancer stigma, but I do not claim to be immune to its insidious and malicious weaving into my own thoughts and actions.
Lung Cancer Control Continuum

- Prevention
- Early Detection
- Diagnosis
- Treatment
- Survivorship

Lung Cancer Stigma
What are your thoughts or feelings about this photograph?
Which lung cancer survivor deserves more empathy and support?
My Lung Cancer Stigma Story...

Mildred Coughlin Blink
1915-2011

Grandma’s Concealed Weapon
What is Stigma?

... a mark of shame or discredit

...a mark of disgrace associated with a particular circumstance, quality, or person.

...an attribute that is deeply discrediting that turns an individual from a whole and usual person to a tainted, discounted one. (Goffman, 1963)

“othering"
What about Lung Cancer Stigma?
Three Types of Health Stigma (Plus One)

- **Perceived Stigma**
  - Recognition of negative appraisal and devaluation from others

- **Enacted Stigma (Bias)**
  - Overt acts of discrimination from others

- **Internalized Stigma (Self-Blame)**
  - Belief that negative attributions are true and deserved

- **Constrained Disclosure**
  - Reduced willingness to discuss diagnosis, restricted support options

(Courtesy of Dr. Heidi Hamann)
What evidence do you have?

How about some examples of lung cancer stigma?
Did you smoke?
Perceived Lung Cancer Stigma

According to the Lung Cancer Project, 3 of 4 people have a negative bias towards people with lung cancer.

Percentage of people who associate lung cancer with:
- Shame: 67%
- Stigma: 74%
- Hopelessness: 75%

https://www.thelungcancerproject.org/
### Patients are Experiencing More Stigma

<table>
<thead>
<tr>
<th>Perception</th>
<th>2008</th>
<th>2018</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel there is a stigma associated with having lung cancer</td>
<td>54</td>
<td>70</td>
<td>p=0.001</td>
</tr>
<tr>
<td>I feel lung cancer patients are viewed or treated differently than other cancer patients are</td>
<td>47</td>
<td>54</td>
<td></td>
</tr>
<tr>
<td>I blame myself for developing lung cancer</td>
<td>49</td>
<td>46</td>
<td></td>
</tr>
<tr>
<td>Strangers/acquaintances have said or done things that I felt were blaming me for my lung cancer</td>
<td>31</td>
<td>51</td>
<td>p&lt;0.0005</td>
</tr>
<tr>
<td>My friends/family have said or done things that I felt were blaming me for my lung cancer</td>
<td>21</td>
<td>29</td>
<td></td>
</tr>
<tr>
<td>I feel that my friends/family would be more supportive of me if I had a different type of cancer</td>
<td>11</td>
<td>24</td>
<td>p=0.001</td>
</tr>
</tbody>
</table>

Jennifer C. King, PhD, Lung Cancer Alliance, USA, @JenniferCKing @LCAorg
Enacted Lung Cancer Stigma

US Cancer Deaths vs. Federal Research Funding per Death

159,480 deaths

50,830 deaths

40,030 deaths

29,720 deaths

Lung

Colorectal

Breast

Prostate

$1,450

$6,118

$20,802

$12,281

Figure ©2013 National Lung Cancer Partnership. All rights reserved.
Enacted Lung Cancer Stigma – II

CDMRP/DOD 2019 Proposed Funding

<table>
<thead>
<tr>
<th>TYPE of CANCER</th>
<th>Projected Deaths</th>
<th>Projected Incidence</th>
<th>Research $ by Death</th>
<th>Research $ by Incidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast Cancer + Semipostal</td>
<td>$130,600,000</td>
<td>42,260</td>
<td>$3,090.39</td>
<td>$486.22</td>
</tr>
<tr>
<td>Melanoma</td>
<td>$10,000,000</td>
<td>7,230</td>
<td>$1,383.13</td>
<td>$103.65</td>
</tr>
<tr>
<td>Ovarian Cancer</td>
<td>$20,000,000</td>
<td>13,980</td>
<td>$1,430.62</td>
<td>$887.71</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>$100,000,000</td>
<td>31,620</td>
<td>$3,162.56</td>
<td>$572.57</td>
</tr>
<tr>
<td>Kidney Cancer</td>
<td>$20,000,000</td>
<td>14,770</td>
<td>$1,354.10</td>
<td>$270.93</td>
</tr>
<tr>
<td><strong>Lung Cancer</strong></td>
<td><strong>$14,000,000</strong></td>
<td><strong>142,670</strong></td>
<td><strong>$98.13</strong></td>
<td><strong>$61.36</strong></td>
</tr>
</tbody>
</table>
Sometimes well-meaning people get it wrong too...

**WHY NOT KIDS?**

- We believe children deserve equal access to life saving research and treatment as adults, **WHY NOT KIDS?**

- $9.8 million was appropriated in the last biennium for lung cancer research, a disease usually diagnosed after decades of smoking, **WHY NOT KIDS?**

*Slide presentation delivered to a budget subcommittee on Health and Family Services in the Kentucky legislature (2018).*
What about lung cancer stigma in clinicians or clinical settings?

• Research has shown that approximately 50% of individuals diagnosed with lung cancer reported feeling stigmatized by their oncologist.
Sample Brief Vignette

Alex is a married 70-year-old with 2 adult children. Last month Alex was feeling fatigued and experiencing persistent headaches, and therefore went to an Urgent Treatment Center. A primary care provider discovered a tumor after ordering an imaging study, and the following biopsy led to diagnosis of a localized lung cancer. Alex has smoked a pack of cigarettes per day for the past 50 years, and reports eating a well-balanced diet. Alex has been scheduled for surgery and adjuvant chemotherapy. Alex seems to be doing well, but is concerned about the impact of cancer treatment on the rest of the family.
Study 1: LC Stigma Ratings (N = 94)

**Pity**
- Smoking: Lung (23), Colorectal (21)
- Not Smoking: Lung (19), Colorectal (17)

(Smoking $p = .001$)

**Helping**
- Smoking: Lung (35), Colorectal (30)
- Not Smoking: Lung (25), Colorectal (20)

(Smoking $p = .001$)

**Anger**
- Smoking: Lung (8), Colorectal (6)
- Not Smoking: Lung (4), Colorectal (2)

(Smoking $p < .001$)

**Comfort**
- Smoking: Lung (8), Colorectal (6)
- Not Smoking: Lung (8), Colorectal (6)
Study II: Lung Cancer Stigma (N = 143)

- Pity
  - Lung vs. Colorectal
  - Interaction p < .05

- Sympathy
  - Lung vs. Colorectal
  - Interaction p < .05

- Concern
  - Lung vs. Colorectal

- Aggravation
  - Lung vs. Colorectal
  - Smoking p < .001

- Anger
  - Lung vs. Colorectal
  - Smoking p < .001

- Irritated
  - Lung vs. Colorectal
  - Smoking p < .001
Lung Cancer Stigma & the Socioecological Model

- Self-Blame & Distress
- Blame & Conflict
- Mistreatment
- Isolation & Disdain
- Neglect & Indifference
Where does lung cancer stigma come from?

• High disease mortality

• Perceived futility of treatment (nihilism)
  “I’m 62 years old. I mean, you know, if I have lung cancer...basically, I just don’t want to know about it.”

• Heightened fear

• Need to distance self from perceived risk

• Lack of survivor visibility

Where does lung cancer stigma come from?

- Association with smoking
  - Intensified by the effectiveness of hard-hitting tobacco control public health campaigns.
  - Seen as self-induced.

Stephen

Great !!
And if you continue to smoke after knowing the health risk there should not be any Medicare benefits.

8 hours ago • Like • 4 • Reply
TIPS™ Campaign from the CDC

• The Tips™ campaign profiles real people who are living with serious long-term health effects from smoking and secondhand smoke exposure.

• Since 2012, the Tips™ campaign has motivated an estimated 500,000 tobacco smokers to quit for good.

• In 2016, the average weekly call volume to 1-800-QUIT-NOW was 92.7% higher than the average call volume during the two-week baseline period, representing almost a doubling of call volume.

• What has been the impact of the TIPS™ campaign on individuals suffering from tobacco-related illnesses?
  • Was this considered during message design?
  • What might be non-stigmatizing messages?

https://www.cdc.gov/tobacco/campaign/tips/
Youth Tobacco Prevention

(Deena Cook, Lung Cancer Survivor and Advocate)
Countering Lung Cancer Stigma

Self-Reflection

Preparation

Empathy

Vigilance
Countering Stigma

- Society
- Systems
- Clinicians
- Family & Friends
- Survivors
- At-Risk Individuals
Self-Reflection

Regardless of your role as clinician, advocate, researcher, caregiver, organizer, or other, it is worth some time to reflect on your personal thoughts, attitudes, and actions related to tobacco and lung cancer.

• How do I think, feel, and act with regard to...
  • Individuals using tobacco?
  • Individuals using tobacco in restricted areas?
  • Individuals diagnosed with other stigmatized conditions?
Preparation: Countering Stigma

Empowering Survivors

Advice from lung cancer survivors on the ever common question...

“DID YOU SMOKE?”

- Don’t take it personally
- Rise above
- Educate
- Ignore
- Does it matter?

LUNG CANCER ALLIANCE
Stigma-Free Principles

Could we develop stigma-free principles for implementing & delivering health care services?

- Could be used to inform care pathways
- Could be used to train clinicians
- Could be used to design clinics and hospitals
- Could be used to inform clinic and hospital policy
- Could be used to guide community engagement and education
Stigma-Free Lexicon

Can we create a stigma-free game-plan for how to talk about tobacco, lung cancer, lung cancer risk, and other aspects of lung cancer care?

• Could be used to guide awareness & media campaigns

• Could be used to educate & train clinicians & caregivers

• Could be embedded in early health education efforts

• Could be provided to patients and survivors
Empathic Communication

• As clinicians, advocates, researchers, and caregivers, how we talk about tobacco, lung cancer risk, and lung cancer is extremely important and influential.

• There is ongoing research into how we can be more empathic in discussing tobacco use and other stigmatizing aspects of care.

• There is also work considering how we communicate publicly about tobacco and lung cancer.
Empathic Clinical Communication Skills

1) Agenda setting

2) Questioning and history taking

3) Recognizing or eliciting patient’s empathic opportunities

4) Working towards a shared understanding of the patient’s emotion or experience

5) Empathically responding to the emotion or experience

6) Facilitating coping and connecting to social support

7) Closing the conversation

(Pehrson et al., 2016; Banerjee et al., In press)
Reframing the Conversation

IF THEY HAVE LUNG CANCER. Many people believe that if you have lung cancer you did something to deserve it. It sounds absurd, but it’s true. Lung cancer doesn’t discriminate and neither should you. Help put an end to the stigma and the disease at NoOneDeservesToDie.org.

(Courtesy Angela Criswell, Lung Cancer Alliance)
The Contact Hypothesis
Intergroup Contact Theory

• Under certain conditions, interpersonal contact could be an effective manner of reducing prejudice between group members

• Positive Contact/Interaction
  1) Equal Status
  2) Common Goals
     • Superordinate Goal
  3) Intergroup Cooperation
  4) Acknowledge Authority

• Reconceptualizing groups, reducing generalizations and prejudice

• Caring
  • With compassion and embracing lung cancer survivors during care

• Championing
  • Lung cancer survivors throughout survivorship

• Creating
  • Easy opportunities for lung cancer survivors to engage advocacy

• Confronting
  • Bias and stigma when identified, de-normalizing

• Conversing
  • About lung cancer, accepting and normalizing

(Gordon Allport, 1954)
Keytruda (pembrolizumab) by默沙东

ImmunoTherapy for Lung Cancer

Learn About KEYTRUDA

Side Effects

Financial Assistance

Patient Story

Get Patient Support

Sign Up for Updates

Twitter | Email

ActiS portrait of a real patient from the clinical trial.

Keytruda is a programmed death-ligand 1 (PD-L1) checkpoint inhibitor therapy approved for the treatment of people with nonsquamous non-small cell lung cancer (NSCLC), who have progressed following chemotherapy.

A CHANCE FOR A LONGER LIFE.

It's True. Keytruda.

Keytruda does not work for everyone. Results may vary.

For advanced non–small cell lung cancer that has high levels of PD-L1, Keytruda could be your first treatment option instead of chemotherapy.

See Clinical Trial Results

Other Indications

This site is intended for U.S. residents 18 years of age or older.

1-855-OPDIVO-1 | SIGN UP | CHAT

For U.S. Healthcare Professionals | U.S. Full Prescribing Information | Medication Guide | Full Indication

If you have a type of advanced-stage lung cancer, this is big.

Advanced Non-Squamous NSCLC Trial

In a clinical trial of 582 patients whose advanced non-squamous NSCLC had spread or grown after treatment with platinum-based chemotherapy, 237 were treated with Keytruda, and 245 were treated with chemotherapy (docetaxel). Keytruda was shown to reduce the risk of dying by 27% compared to chemotherapy (docetaxel) Half of the patients on Keytruda were still alive at 12.2 months, compared to

Advanced Squamous NSCLC Trial

In a clinical trial of 272 patients whose advanced squamous NSCLC had spread or grown after treatment with platinum-based chemotherapy, 135 were treated with Keytruda, and 137 were treated with chemotherapy (docetaxel). Keytruda was shown to reduce the risk of dying by 41% compared to chemotherapy (docetaxel). Half of the patients on Keytruda were still alive at 9.2 months, compared to 6 months with chemotherapy (docetaxel).
The National Lung Cancer Roundtable (NLCRT) is a national coalition of public, private, and voluntary organizations, and invited individuals, dedicated to reducing the incidence of and mortality from lung cancer in the United States, through coordinated leadership, strategic planning, and advocacy.

Task Groups (10)
1) Advanced Imaging
2) Lung Cancer in Women
3) LCS Implementation Strategies
4) Policy Action
5) Provider Engagement and Outreach
6) Shared Decision Making
7) State-Based Initiatives
8) Survivorship, Stigma, and Nihilism
9) Tobacco Treatment in LCS
10) Triage for Appropriate Treatment

2019 Annual Meeting
Date: December 9-10, 2019
Location: Capital Hilton, Washington DC

https://nlcrt.org/about/roundtable-membership-app/
Conclusions

1) **Lung cancer stigma** is a pervasive and destructive aspect of American culture and health care.

   *(Patently: lung cancer stigma kills)*

2) **Research** is necessary to develop, evaluate, and inform the development of evidence-based interventions at multiple levels.

3) **Advocacy** is desperately needed to promote empathy, compassion, and support for individuals at-risk for lung cancer as well as individuals and families who have experienced a diagnosis.

4) **Lung cancer stigma** can be addressed, reduced, and eliminated with wisely applied data, compassion, and persistence.

5) How can we **work together to confront lung cancer stigma** and reduce the burden of lung cancer?