

# LUNG CANCER PATIENT SUPPORT ECHO SESSION 10

## STIGMA AND PSYCHOSOCIAL ISSUES

JAMIE STUDTS, PH.D.  
JAMIE OSTROFF, PH.D.

THOMAS ASFELDT, RN, MAN, MBA (FACILITATOR)  
FEBRUARY 28, 2019  
9:00 AM ET



Comprehensive  
Lung Cancer  
Patient Support Program

Supported in part by the Bristol-Myers-Squibb Foundation



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# TODAY'S AGENDA

Time	Presentation	Presenter (s)
9:00-9:10	Welcome, roll call, housekeeping	Thomas Asfeldt, RN, MAN, MBA
9:10-9:45	Didactic Presentation: ECHO Session 6	Jamie Studts, Ph.D. Jamie Ostroff, Ph.D.
9:45-10:00	Q & A/Discussion	Thomas Asfeldt
10:00-10:15	Program/Case Presentation:	Melissa Hutchison, ACS Navigator
10:15-10:25	Q & A/Discussion	Thomas Asfeldt
10:25-10:30	Conclusion/Next session	Thomas Asfeldt Dawn Wiatrek Octavia Vogel

\*Sessions will be recorded.

\*Please mute phones when not speaking. Mute cell phones and try to reduce extraneous noise.

\*Remember to e-mail Octavia Vogel by 3/4 if you are requesting CME/CEU credit.

# DISCLOSURE

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- The following planners and faculty disclose that they have no financial relationships with any commercial interest: (next slide)

# FACILITATOR & PRESENTERS

**Presenters:**

**Jamie L. Studts, Ph.D.**

Professor, Department of Behavioral Science  
University of Kentucky College of Medicine  
Director, Behavioral and Community-Based Research  
University of Kentucky Markey Cancer Center  
Kentucky LEADS Collaborative

**Jamie Ostroff, Ph.D.**

Memorial Sloan Kettering Cancer Center Chief, Behavioral Sciences Service  
Director, Tobacco Treatment Program

**Case Presenter:**

**Melissa Hutchison**

ACS Navigator  
Temple University Hospital  
Philadelphia, PA

**Facilitator:**

**Thomas Asfeldt, RN, MAN, MBA**

Director, Sanford Medical Center, Outpatient Cancer Services &  
Radiation Oncology  
Sanford Health

# LEARNING OBJECTIVES

This session will provide an overview of the psychosocial burden of lung cancer, an introduction to the impact of lung cancer stigma, and an overview of approaches to talk about tobacco use in the context of a lung cancer diagnosis

Upon completion of this session participants will be able to:

- 1. Recount the psychosocial burden of a lung cancer diagnosis**
- 2. Describe lung cancer stigma and evaluate its impact on lung cancer care**
- 3. Address tobacco use in the context of lung cancer with empathy**

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# THE PSYCHOSOCIAL BURDEN OF LUNG CANCER

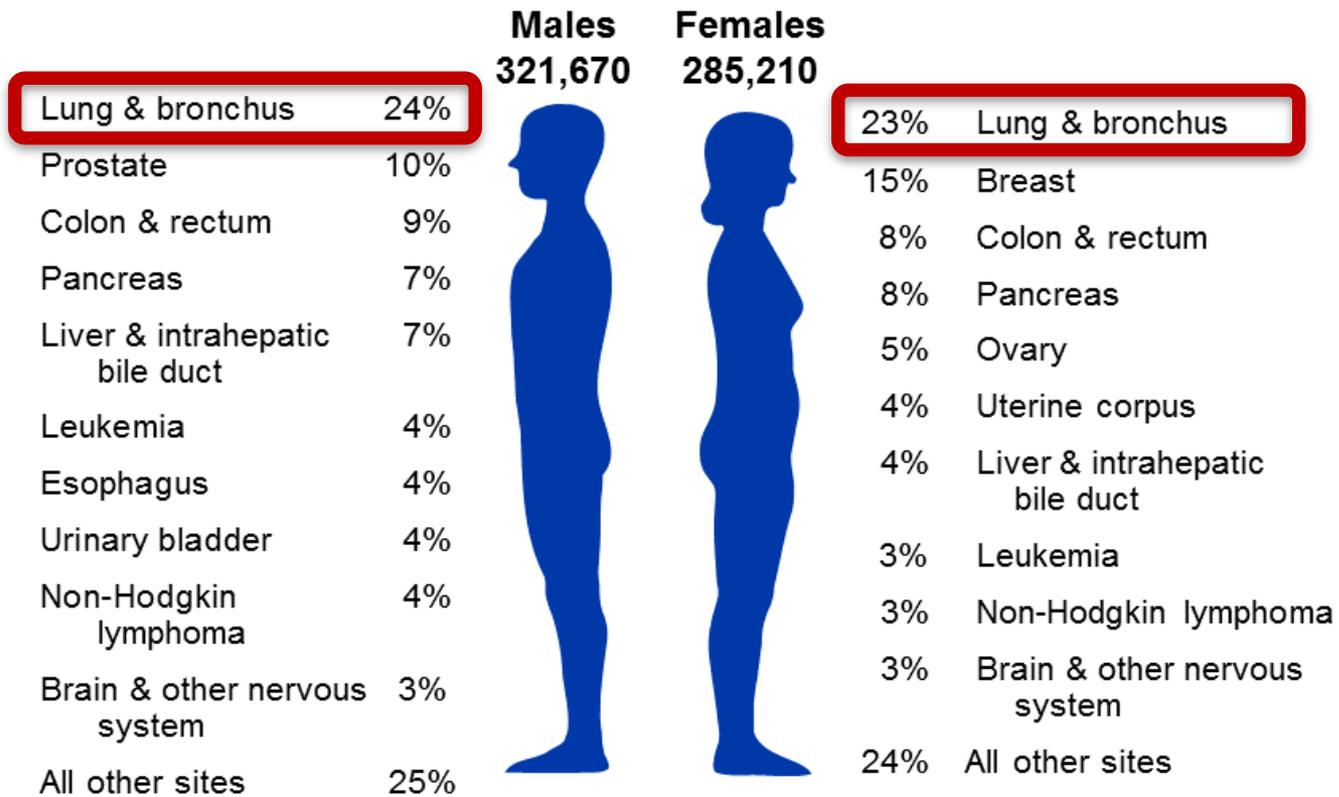
**JAMIE STUDTS, PH.D.**

UNIVERSITY OF KENTUCKY



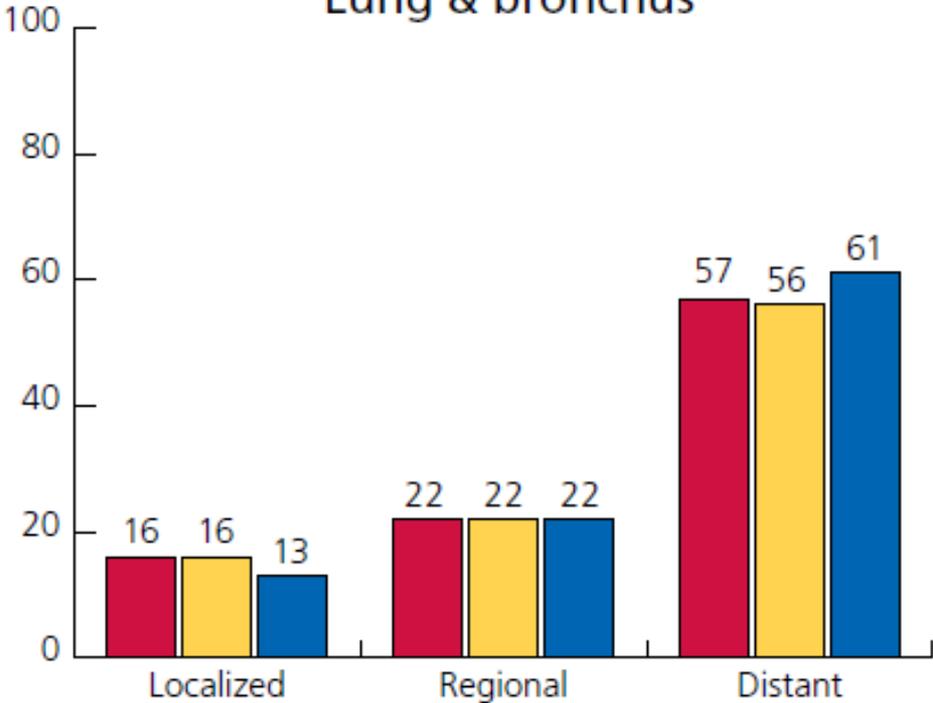
# Estimated Cancer Deaths in US, 2019

## Estimated Cancer Deaths in the US in 2019



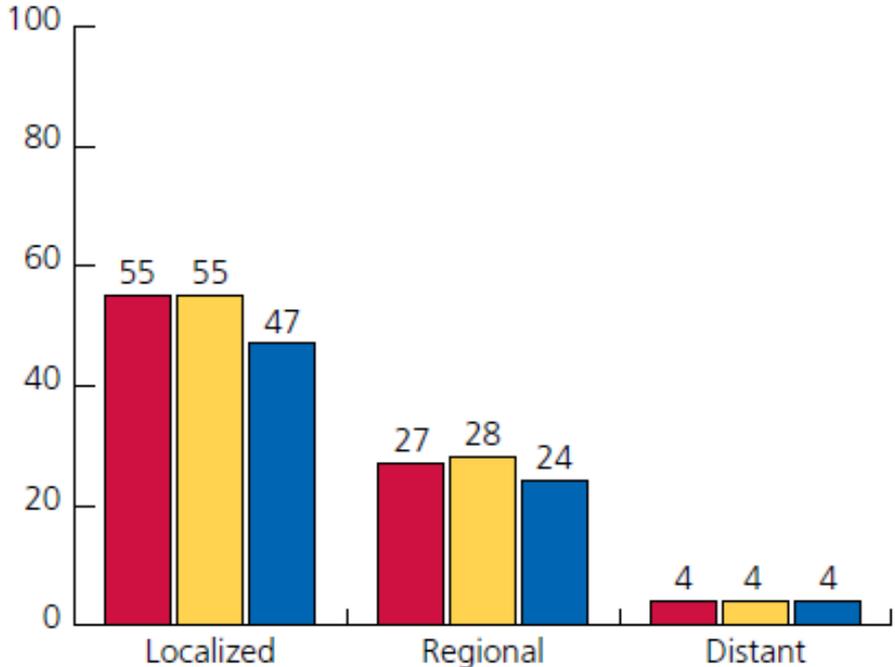
# Lung Cancer: Survivorship Facts

Lung & bronchus



Stage Distribution at Diagnosis by Race  
(2005-2011)

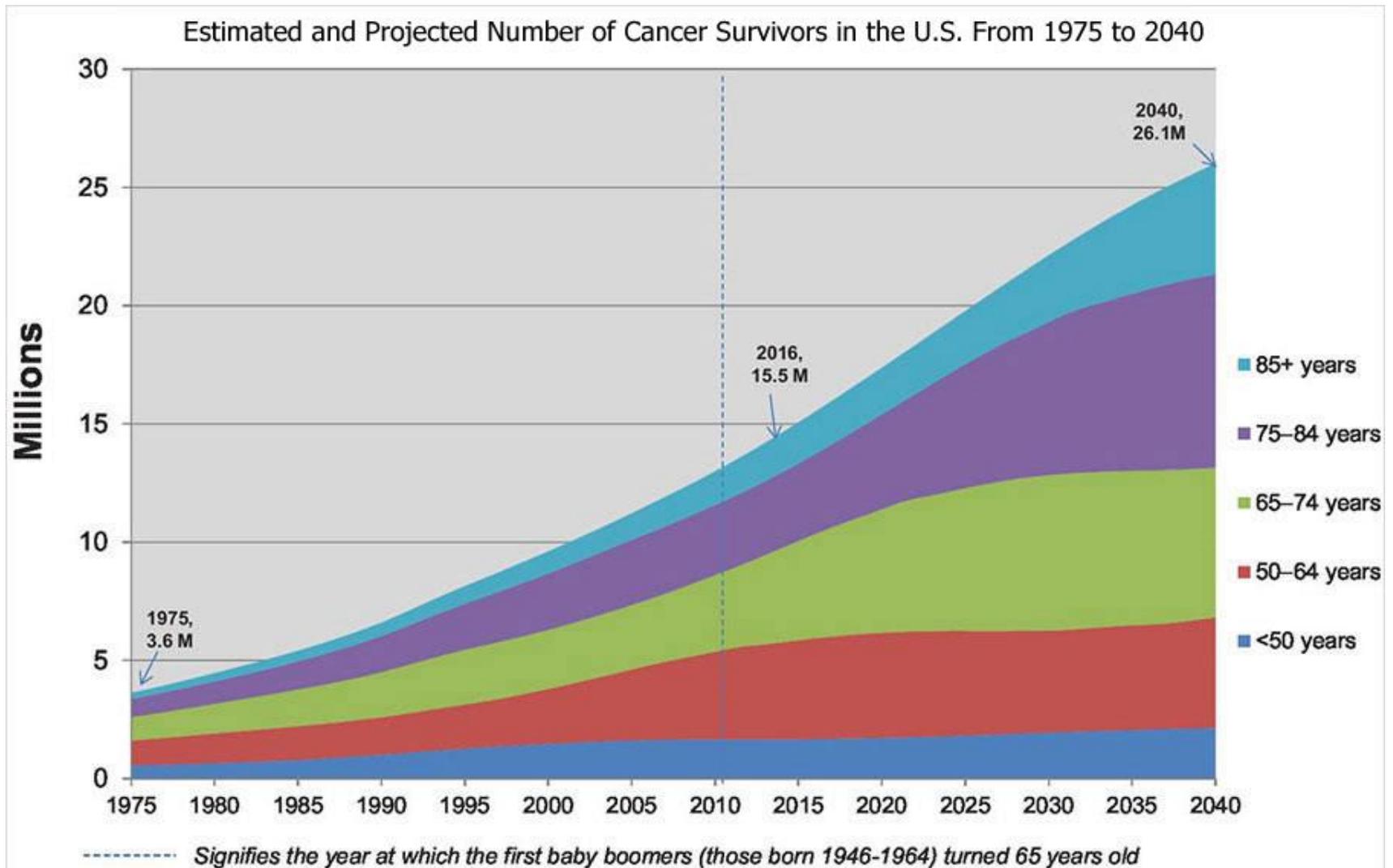
Lung & bronchus



Five-Year Survival Rates by Race/Stage  
(2005-2011)

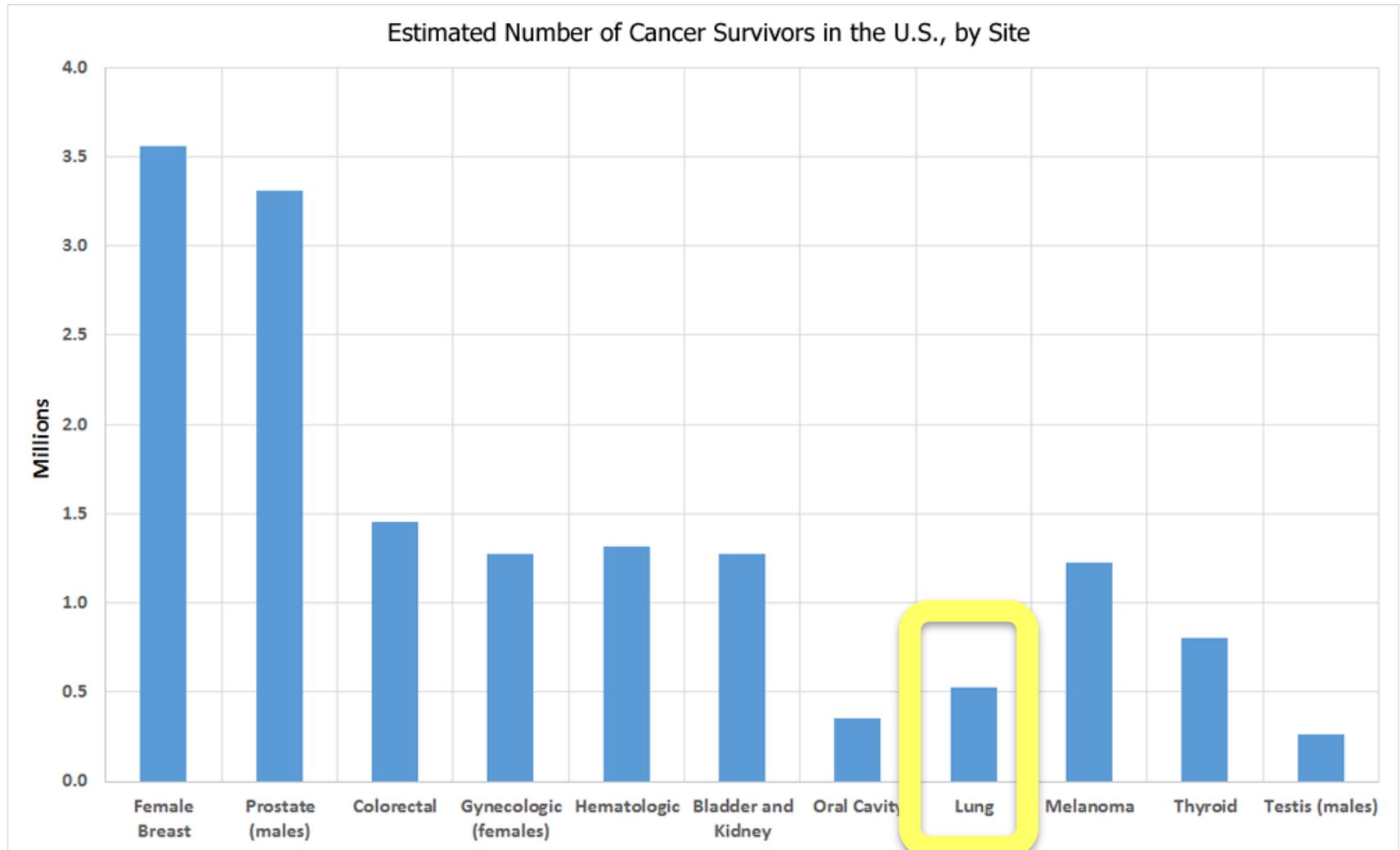
(American Cancer Society, Cancer Treatment & Survivorship Facts & Figures 2016-2017)

# Cancer Survivorship Trends in US



Bluethmann SM, Mariotto AB, Rowland, JH. Anticipating the "Silver Tsunami": Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors in the United States. *Cancer Epidemiol Biomarkers Prev.* 2016;25:1029-1036.

# Cancer Survivorship in the US (by site)



Miller, K. D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H., Stein, K. D., Alteri, R. and Jemal, A. (2016), Cancer treatment and survivorship statistics, 2016. CA: A Cancer Journal for Clinicians.

# *There have been exciting and optimism-inducing innovations in lung cancer care.*

- Minimally Invasive Surgical Procedures (VATS)
- Stereotactic Body Radiation Therapy (SBRT)
- Targeted Therapies & Immunotherapies
- Survivorship and Palliative Care Innovations (Temel Study)
- Targeted Lung Cancer Screening (NLST)
- Additive Tobacco Treatment Strategies



# THREE QUESTIONS

*What is the experience of lung cancer survivors?*

*What would we like the experience of lung cancer survivors to be?*

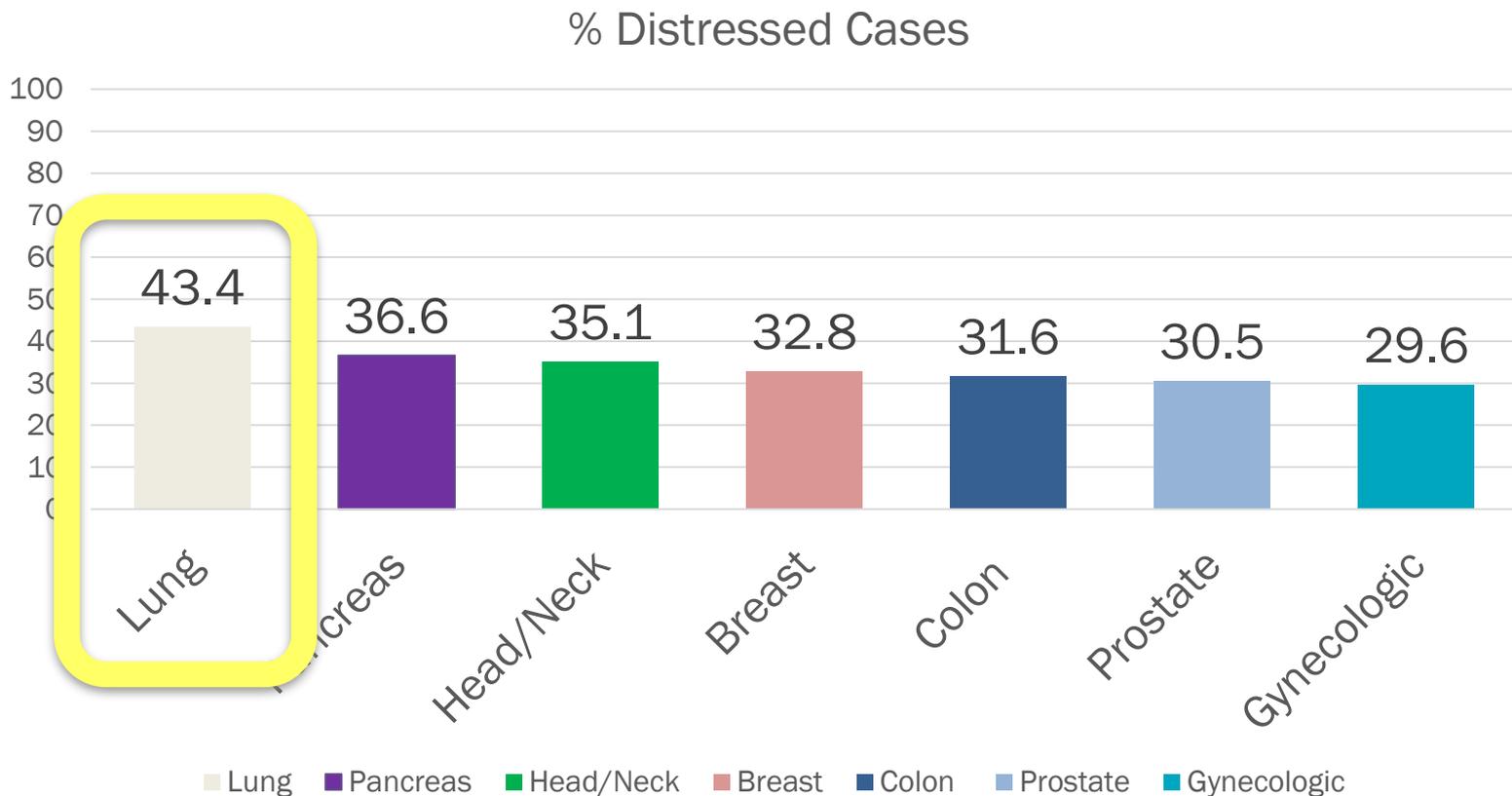
*How should we approach lung cancer survivors?*

# *The Psychosocial Burden of Lung Cancer*

*(for the patient-survivor)*



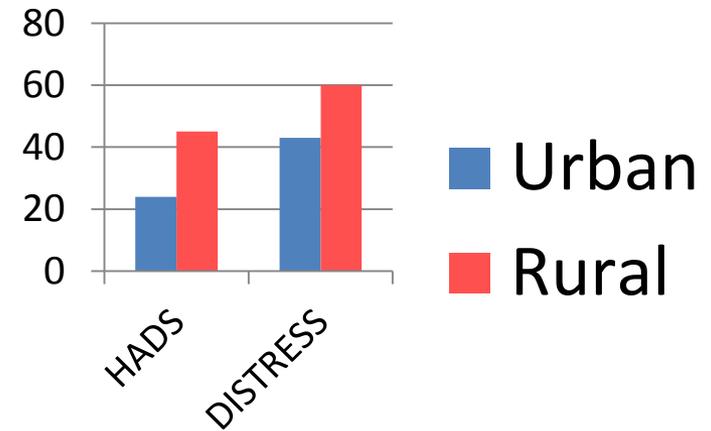
# Individuals diagnosed with lung cancer commonly experience substantial psychological distress.



Zabora, J., Brintzenhofesoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology*, 10, 19-28.

# *Rural-residing lung cancer survivors experience additional challenges.*

- Rural LuCa survivors report poorer mental health relative to Urban LuCa survivors.
- Some evidence suggests poorer access and less use of mental health services and cancer support groups among rural survivors.

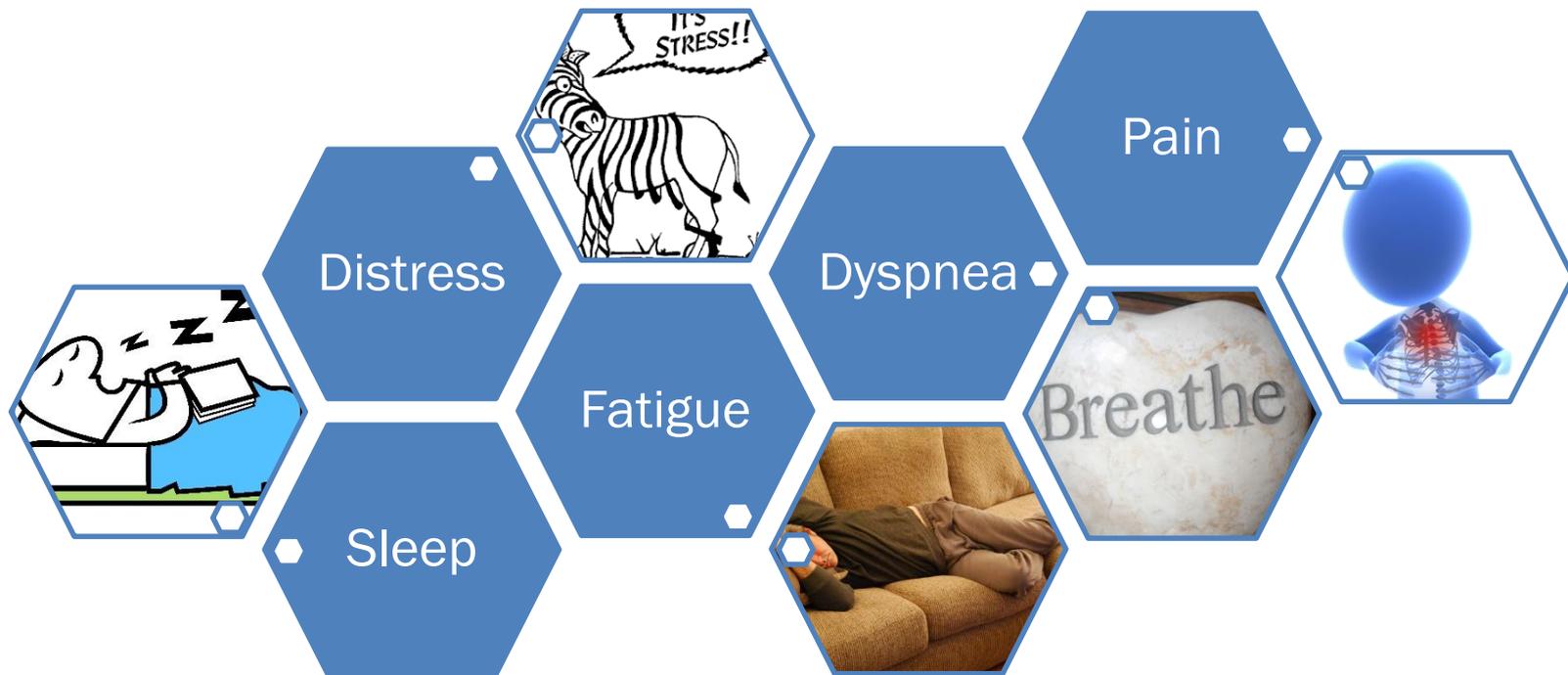


# Lung cancer survivors are less likely to be engaged and actively involved in care.

## Patient Engagement

- Few individuals diagnosed with early stage lung cancer experience shared decision making.  
*Hopmans, et al. (2015). BMC Cancer, 15(1), 959.*
- Noteworthy discordance in perceptions of decision making between individuals diagnosed with lung cancer and clinicians.  
*Hotta, et al. (2010). Journal of Thoracic Oncology, 5(10), 1668–1672.*
- Over two-thirds of individuals receiving chemotherapy for metastatic lung cancer did not understand that their treatment would not be delivered with curative intent.  
*Weeks, et al. (2012). New England Journal of Medicine, 367(17), 1616–1625.*
- Efforts to encourage engagement and activation have been recently initiated but have yet to increase patient activation.  
*Groen, et al. (2016). Journal of Clinical Oncology, 34(3\_suppl), 201.*

# *The physical symptom burden of lung cancer is similarly substantial due to several disease and treatment factors.*



(Pratt Pozo et al., (2014). *Cancer Control*, 21, 40-50)  
(Sanders et al., (2010). *Psycho-Oncology*, 19, 480-489)  
(Sugimura & Yang (2006). *Chest*, 129, 1088-1097)  
(Vijayvergia et al., (2015). *JNCCN*, 13, 1151-1161)

# *Social support plays a vital, but complex role in lung cancer survivors.*

## ■ Social Support

Social support was associated with multiple quality of life domains

Social support from clinicians was associated with physical and emotional QoL

Social support from family/friends was associated with emotional QoL

Luszczynska, et al., (2013). *Psycho-Oncology*, 22(10), 2160–2168.



# *What about social constraints?*

- Individuals diagnosed with lung cancer and their spouses reported a wide variety of social constraints, including denial, avoidance, and conflict that can hinder open spousal communication.
- Specifically, patients and spouses reported trouble discussing continued tobacco use, cancer-related symptoms, prognosis, and the emotional effects of lung cancer on the spouse.



# Individuals diagnosed with lung cancer face substantial stigma and bias.

## ❖ *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 option



# Lung Cancer Stigma and the Socio-Ecological Model

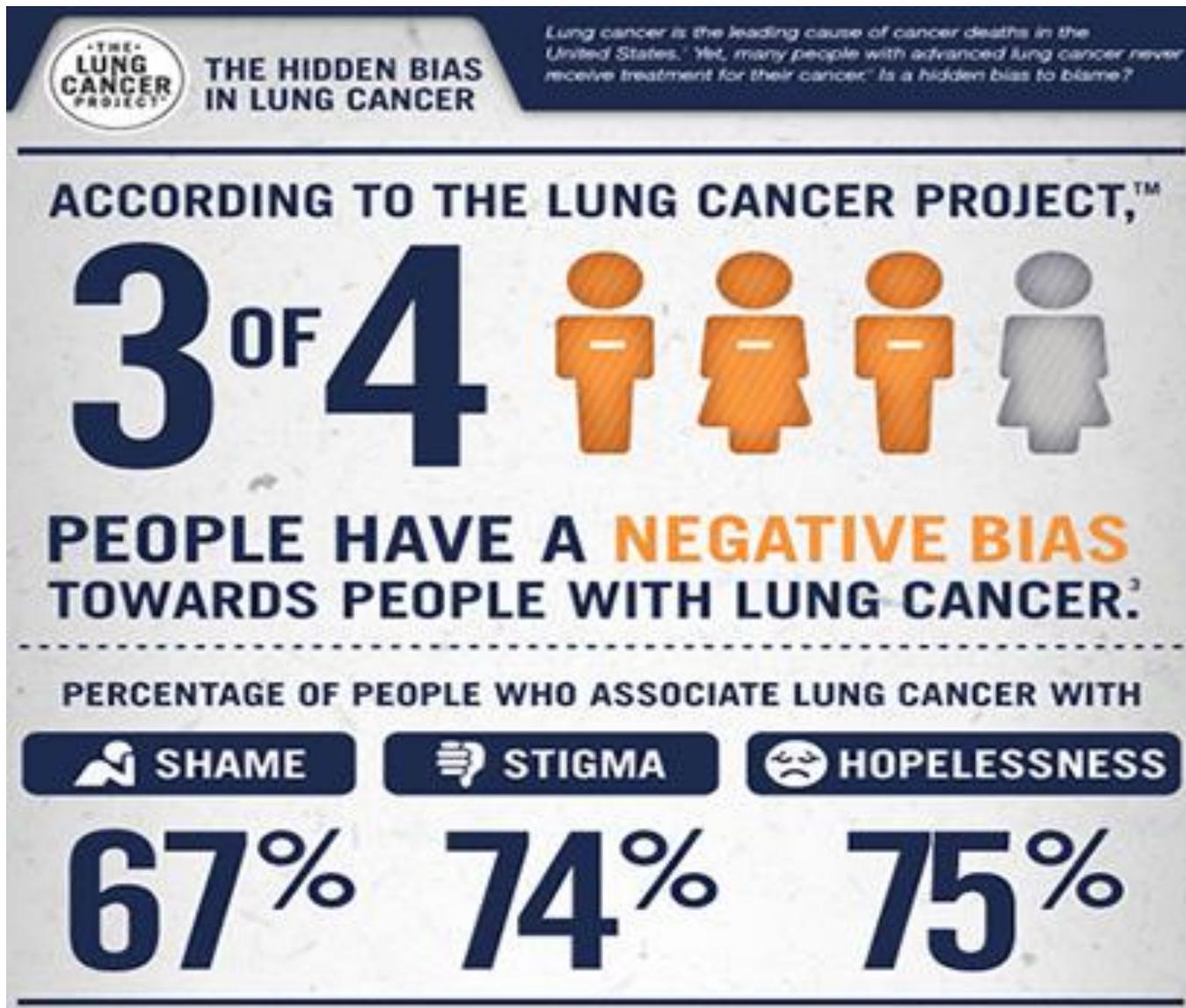
## Socio-Ecological Model



# Internalized Lung Cancer Stigma

- Among individuals who have lung cancer who harbor internalized stigma and self-blame...
  - 1) they may not be as engaged with treatment decisions,
  - 2) they may not communicate symptoms or side-effects to clinicians,
  - 3) they may experience higher levels of distress,
  - 4) they may not engage social supports,
  - 5) they may not adhere to treatment recommendations, and
  - 6) they may experience poorer health outcomes (broadly defined).

# Perceived Lung Cancer Stigma



# Enacted Lung Cancer Stigma

## US Cancer Deaths vs. Federal Research Funding per Death <sup>1, 8-9</sup>

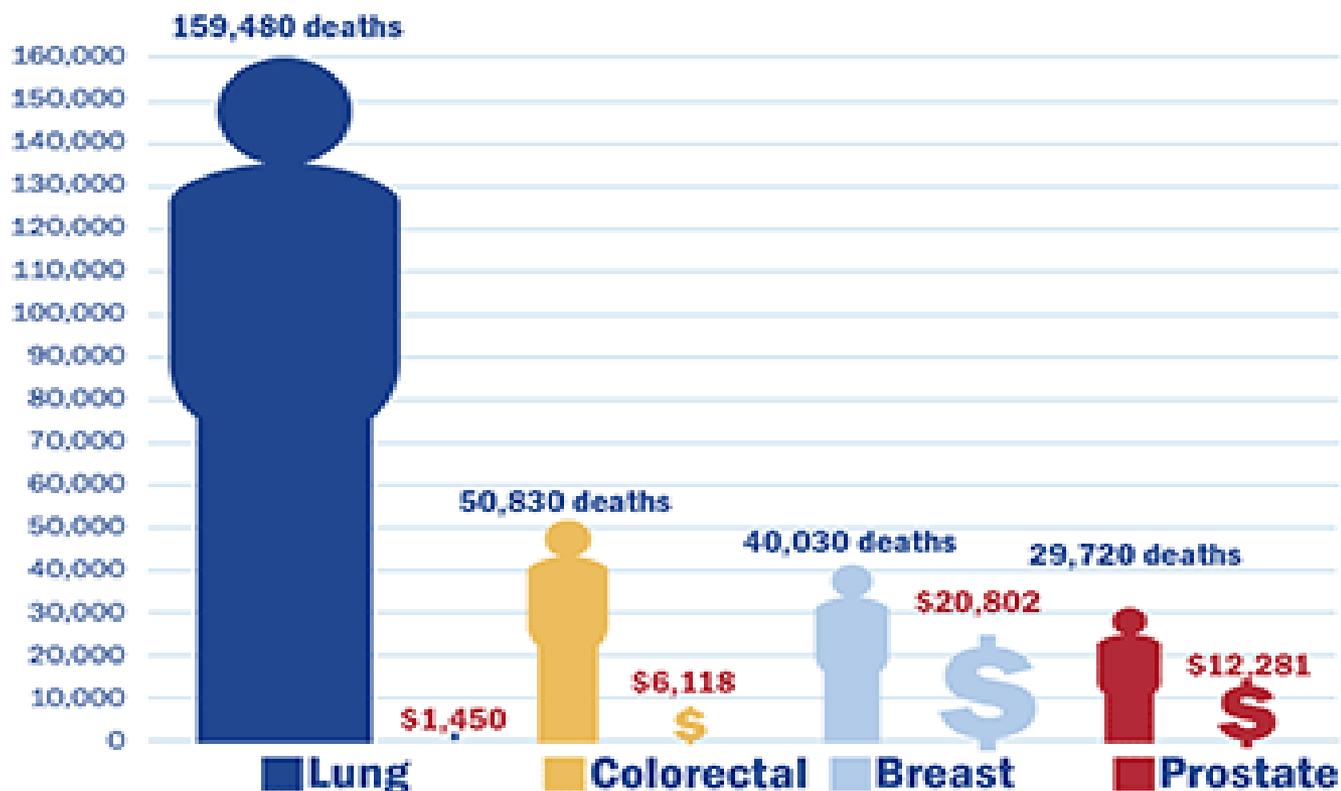
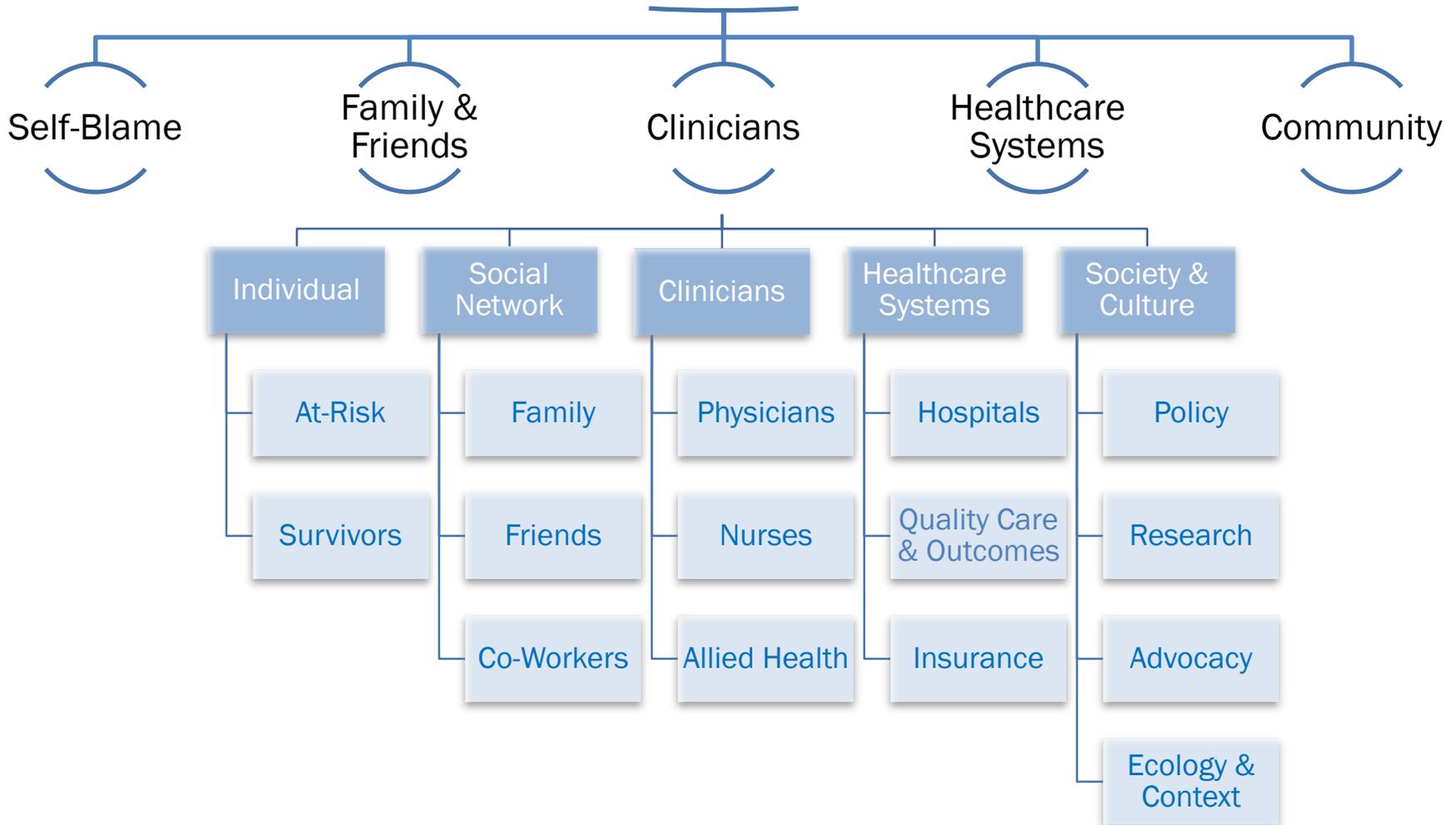


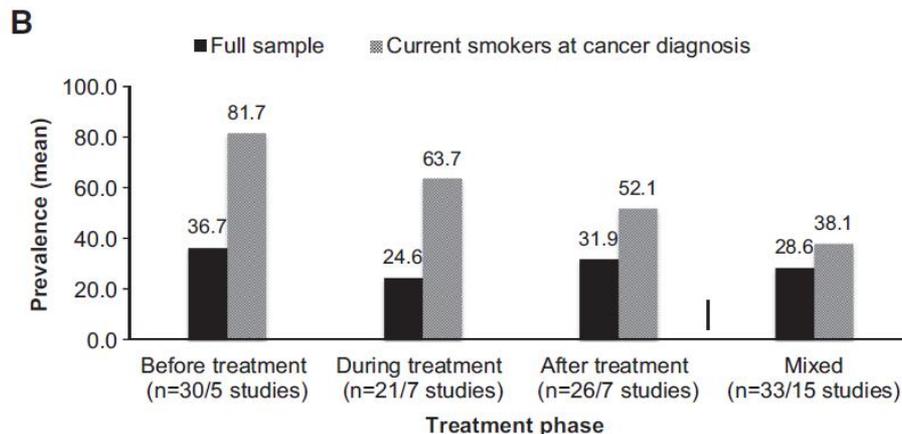
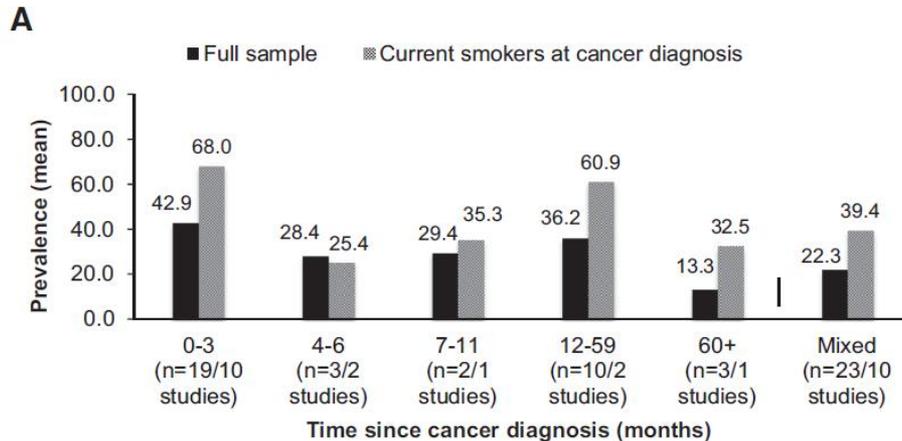
Figure ©2013 National Lung Cancer Partnership. All rights reserved.

# Lung Cancer Stigma



***Raising Awareness and Educational Efforts***

# Individuals diagnosed with lung cancer demonstrate a range of risky behaviors.



- Systematic review of studies addressing tobacco use following diagnosis of lung or head/neck cancer.
- Approximately 1/3 of all individuals with lung or head/neck cancer continue to use tobacco.
- Over half of individuals who use tobacco at baseline continue to use

# Physical Activity and Lung Cancer



Bade et al. (2015). Increasing physical activity and exercise in lung cancer: Reviewing safety, benefits, and application. *Journal of Thoracic Oncology*, 10, 861 – 871.

# Physical Activity and Lung Cancer

- Physical activity should be therapeutic option for LC survivors:
  - Reduces symptoms
  - Improves exercise tolerance
  - Enhances quality of life
  - May reduce length of hospital stay
  - May reduce complications following surgery.
- The majority of lung cancer patients want guidance from their physicians regarding physical activity and exercise
- Treating clinicians should prescribe activity/exercise before, during, and after lung cancer diagnosis and treatment.



# How should we think about lung cancer survivors?

## ■ Lung Cancer Survivors are likely to experience:

- 1) ...clinically-relevant levels of distress
- 2) ...prominent symptom burden
- 3) ...multiple health-compromising behaviors
- 4) ...substantial stigma as well as self-blame
- 5) ...lower levels of social support (complicated)
- 6) ...substantially **less** engagement and motivation for care
- 7) ...barriers to access care, survivorship care, in particular



*Deserving of the same compassion, empathy, support, and evidence-based interventions traditionally available to individuals diagnosed with other cancers.*

# Summary

- 1) Lung cancer diagnosis and treatment carry substantial psychosocial and symptom burden.
- 2) In addition, a variety of socio-cultural issues play prominent roles in reducing social support and empathy among individuals diagnosed with lung cancer.
- 3) These issues have received substantially less attention from researchers, clinicians, and advocates in comparison to other malignancy populations.
- 4) Innovations and improvements in lung cancer care create (and even demand) a new focus on lung cancer survivorship issues that impact quality of life as well as morbidity and mortality.
- 5) Opportunities abound for addressing the psychosocial burden of lung cancer.



# THANK YOU!

You may email questions to:

[jamie.studts@uky.edu](mailto:jamie.studts@uky.edu)

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<TITLE OF TALK>

**JAMIE OSTROFF, PH.D.**

MEMORIAL SLOAN KETTERING CANCER CENTER



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# CASE PRESENTATION

MELISSA HUTCHISON, ACS NAVIGATOR

TEMPLE UNIVERSITY HOSPITAL, PHILADELPHIA PA



# CASE PRESENTATION

**68 y/o Caucasian male, stage IIIA lung cancer, dx July 2018**

**Smoker- Pre dx smoked 1 ½ packs daily, post dx smokes ½ pack daily. Smoked since 16 years old**

**Many quit attempts, longest being 5 months**

- Reports SOB for 20 years, Dx with COPD when he was in late 50's. Did notice SOB getting worse for past few months, thought it was because he was getting old or COPD getting worse .Didn't think it could be cancer- especially since he was seeing doctors on a regular basis.- "The doctors will catch it"
- DX after falling and getting x-ray to see if he had broken anything. Initially did not want to tell daughters, as they have always told him he would get cancer if he didn't stop smoking . "Don't call me if you get cancer"
- Daughters did come to first appointment, clearly cared about their father, but did blame him for the diagnosis in the appt- Many "I told you so statements"
- Successfully completed treatments, but came alone most of the time. When more support was needed he did not want to bother daughters for help, and relied on us to coordinate resources and support

# LUNG CANCER IN MY POPULATION/THINGS I COMMONLY SEE & HEAR

## - Comorbidities & Mental Health:

- Most of my lung cancer patients come with a long list of other dx's such as COPD, high BP, etc...
- Tend to be my sickest patients, requiring more time to coordinate care & resources
- Many patients have co-occurring mental health or substance abuse disorders
- Tobacco Abuse

## - Social Support:

- Many patients have families that are giving them the “tough love treatment” and not giving support until they quit smoking.
- Family can be angry and blame patients and are not always a positive support
- Viewing patient's continued smoking as them not caring

## - Financial:

- Many Medicaid/underinsured patients- making well below poverty threshold.
  - Some medications can have high copays, and some insurances do not cover supplements that may be needed for weight stabilization.
  - Financial Support for lung cancer patients can be hard to find, and often exhausted
- Attitude toward patients needing financial help: “If you can afford cigarettes, you can afford\_\_\_\_\_”

## Other Things to Consider:

- “If you cut into it, it will spread”
- “ Lung cancer kills you fast, and chemo will just make you die faster”
- Judgement- From all sides, including treatment providers and those coordinating care
- Patients and caregivers spend a lot of time dwelling on the past “If I didn't smoke, If I stopped sooner”, rather than the “where do we go from here”

**JOIN US FOR LUNG CANCER PATIENT SUPPORT ECHO SESSION 8**  
**LUNG CANCER TREATMENT:**

**MANAGING SIDE EFFECTS AND SYMPTOMS OF LUNG CANCER**

**FACILITATOR:**

**THURSDAY, MARCH 28, 2019**  
**9:00 AM ET**

**Presenters:**

**Kevin Oeffinger, MD**

**Director, Duke Center for Onco-Primary Care**  
**Director, Duke Supportive Care and Survivorship Center**  
**Duke Cancer Institute**

**Professor of Medicine, Division of Medical Oncology**  
**Department of Medicine, Duke University Medical Center**

**Michael D. Stubblefield, M.D.**

**Medical Director for Cancer Rehabilitation – Kessler Institute for Rehabilitation**  
**National Medical Director for ReVital Cancer Rehabilitation – Select Medical**  
**Clinical Professor, Department of Physical Medicine and Rehabilitation –**  
**Rutgers New Jersey Medical School**