Lung Cancer Stigma in Primary Care

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Most importantly...

• Thank you to all the participants who shared their story and provided their thoughts and opinions about this important topic in our research studies.
What do both of these patients stories have in common?

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Common Thread

Focus Group Study (2014)

Lung Health Study (2015)

Opt Out Study (2016)

LuCaS Study (2017-2020)

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Focus Group Study

- 4 groups (screening-eligible long-term current and former smokers)
  - 2 groups screened
  - 2 groups unscreened
- Explored knowledge and beliefs about lung cancer risk and lung cancer screening

- Major Findings:
  - Confusion about risk factors
  - Unaware lung cancer screening existed or confused about how it is performed
  - Smoking-related stigma as a barrier to screening
  - Distrust of the healthcare system

Common Thread

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Lung Health Study

- Survey study with 497 screening-eligible people nationwide
- Examined different variables related to lung cancer screening
  - Health Beliefs (perceived risk, perceived benefits, perceived barriers, self-efficacy)
  - Stigma
  - Healthcare provider recommendation
  - Social influence
  - Knowledge

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What Seems to Matter

- Stigma
- Perceived Benefits, Perceived Barriers, & Self-efficacy
- Healthcare provider recommendation
- Knowledge
- Age

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Opt Out Study

- Qualitative Study (N=19)
- 1:1 Interviews with screening-eligible patients who received a recommendation from PCP to screen and opted out
- Reasons for opting out:
  - False Positives
  - Stigma / feeling blamed for having a smoking history
  - Perceived Low Value
  - Knowledge Avoidance

Common Thread

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LuCaS Study

• **Mixed Methods Study**
  – Survey (N=551)
    – Multiple variables including perceived stigma
  – 1:1 Interview (N=40)
    – Tailored interviews based upon scores on specific variables

• **Preliminary Findings**
  – **Stigma** associated with decision not to screen for lung cancer regardless of race, gender, or age
  – Participants who scored high on stigma scale described being blamed by their healthcare provider and/or family and friends

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The Common Thread

Stigma

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What do patients say about lung cancer?

• “My doctor would literally sniff me…I would go in for a sore throat and she’d open the door and say ‘still smoking’? Well hello, doctor, good to see you too.”

• “My doctor made me feel like a social outcast…like an idiot or stupid or something for smoking. Made me feel like I deserved lung cancer. I don’t deserve lung cancer.”

• “I went to my primary care doctor shortly after being diagnosed with lung cancer and when she found out she said ‘why didn’t you tell me you smoked?’ I didn’t smoke, but the look in her eye…she didn’t believe me.”
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