

Shame and pain: Lung cancer's stigma exerts psychic and physical toll

January 5 2021, by Christine Phelan Kueter



Lee Ann Johnson researches the stigma attached to lung cancer, in the hope that patients don't endure additional suffering at the end of their lives. Credit: Christine Phelan Kueter, UVA Nursing

Lung cancer kills more than 150,000 Americans each year, accounting

for a quarter of all cancer deaths, and remains the nation's No. 1 cancer killer. Though few survive it—just 4.5% to 8% remain alive the five years following their diagnoses—stigma and shame surrounding the disease are rampant.

Although many patients with [lung](#) cancer were smokers, even those who never took a puff—like University of Virginia nurse scientist Lee Ann Johnson's mother, Donna King, who died of the disease in 2008—often feel chastened by others and blamed for their disease. That [stigma](#), Johnson found in her research, not only robs them of [quality of life](#), it makes them less likely to seek relief in palliative and end-of-life care, a tide of suffering Johnson hopes to turn.

Here, Johnson speaks to UVA Today about her work.

Q. Your interest in lung cancer is pretty personal.

A. It is. It sounds dramatic, but it's true. My promise to my mom on her deathbed was that I could "fix lung cancer" (she also made me promise to find a man, buy a house and have babies). That kept it broad, but I feel like my focus on palliative and end-of-life care for patients with lung cancer fulfills that final promise to her. She is the reason I have my Ph.D. in nursing, and why my dissertation was related to stigma and advanced lung cancer.

My mom was a never-smoker and, over the years, I noted [that] when I told anyone my mom had or died from lung cancer, the first thing out of their mouth was, "Did she smoke?" With other cancers, the first response is always how the person was sorry for my loss. It became more than an annoyance.

And things came full circle for me. The day I turned in my dissertation, my grandfather, Bob Robinson, was diagnosed with terminal lung

cancer. At that point, I moved back to Arkansas to care for him while finishing up and defending my dissertation. I used to drive my son around until he fell asleep (he was one at that time, and I also was pregnant) and then work on edits in the McDonald's parking lot. My grandfather—who quit smoking in 1970—died in 2015, a few days after I defended my dissertation, and I'm honestly convinced he held on long enough to see me finish my degree.

Q. How does stigma impact people with lung cancer?

A. Stigma stirs people's shame and prevents them from accessing pain- and symptom-relieving palliative and end-of-life care, even when they desperately need it. And given that advanced lung cancer is almost always terminal—fewer than one in 10 people are alive five years after being diagnosed—it's critical to examine factors that may influence and contribute to their quality of life. They don't have long to live, and the collective "we"—their loved ones, nurses and other care providers—need to make sure that beyond managing their symptoms, their mental and social well-being is intact, too.

Q. What did you find in your research on stigma's impact on individuals with lung cancer?

A. Previous studies found that between 30% and 95% of lung cancer patients felt stigmatized by the disease. I took that work one step further by querying individuals who'd been diagnosed with lung cancer to see whether stigma itself inhibited the care they sought and received, and what specific factors seemed to be associated with that stigma.

I received an American Cancer Society grant to fund the research. With that, I asked 62 patients with either stage III or IV [lung cancer](#) whether they felt people avoided them because of their cancer, whether they

perceived that others looked at them as "less of a person" and whether they perceived they were to blame for their disease.

Most were women (37), most were highly educated (27 had at least a [college degree](#)) and most reported a history of smoking (41). One-third reported high levels of stigma, a group that also experienced more frequent feelings of distress, depression and anxiety, fewer meaningful relationships and less enjoyment of life.

The verdict's still out on whether the higher-stigma-experiencing patients had a greater symptom burden (more pain, more depression and so on). It all points to the fact that we clinicians have a lot more work to do to support these patients. Lung [cancer](#)-related stigma is generally not part of a typical nursing assessment, but there's evidence to suggest it'd benefit people, isn't complex and can easily incorporated into routine care. It's exactly the kind of space where a nurse makes every kind of difference.

Provided by University of Virginia

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