

# The Lung Cancer Blame Game

The shame, blame and stigma surrounding this deadly disease affect everything from patient follow-through to research funding.

November 28, 2017 By Diana Mapes

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*Editor's note: November is Lung Cancer Awareness Month, but sadly, many people are still not aware that anyone with lungs can be diagnosed with lung cancer, whether they smoked or not. We're bringing back this piece, [originally published](#) by Fred Hutch News Service in May 2015, about the stigma associated with the disease. Please share with your community.*

When Sherry Stoll\* was diagnosed with breast cancer in late 2011, her community rallied around her. Friends, family and even strangers sent fruit baskets, handmade blankets, get-well cards and restaurant gift cards so she wouldn't have to worry about cooking meals while going through chemo and radiation.

It was an interesting experience for the 53-year-old from Pittsburgh, especially since it wasn't her first bout with cancer. A year and a half earlier, she was diagnosed with lung cancer.

The response from her community then? Crickets.

"There was definitely a lack of support and sympathy," said Stoll, a stay-at-home mom who now runs the nonprofit lung cancer advocacy group, [We Wish](#). "My family was there for me, but most people when they heard about it, were like, 'Wow, that's really a shame. Did you smoke?'"

Most people know that lung cancer is an aggressive killer, caused by a number of factors including smoking, genetic mutations and environmental exposures to [carcinogens like radon](#) and [asbestos](#). But more and more patients, doctors and researchers are pointing to another harmful influence contributing to the suffering, delayed diagnosis and possibly even early deaths of those hit with the disease: stigma.

## Leading cause of death

Lung cancer is the leading cause of cancer deaths in the U.S. Most patients are diagnosed late (symptoms usually don't present until the cancer is advanced) and [screening](#) methods that can detect the disease at earlier, more curable stages have only very recently become available.

This year alone, about 221,000 people will be handed a lung cancer diagnosis and half will die

within a year. All told, lung cancer kills more people every year than breast, colon, prostate and pancreatic cancers combined. Its five-year survival rate is a meager 17.8 percent. Five-year survival rates for breast and prostate cancers are 90 and 99 percent, respectively.

Sadly, funding for lung cancer research is as low as the death rate is high. According to a [2013 post](#) on the website for the American Society of Clinical Oncology, or ASCO, “many individuals will spend more annually on round-trip airfares than either the U.S. or the United Kingdom spends on research per lung cancer death.”

Why the paucity of funding for lung cancer research?

Many point to its association with smoking, even though lung cancer is not exclusively a smokers’ disease. According to research, anywhere from [15 percent](#) to [25 percent](#) of people diagnosed with the disease have never smoked.

Still, a pervasive stigma exists, a phenomenon aptly described by a team of Oxford researchers in one of the first studies on the subject.

“Whether they smoked or not, [patients] felt particularly stigmatized because the disease is so strongly associated with smoking,” they wrote in a [2004 paper](#) in BMJ. “Interaction with family, friends and doctors was often affected as a result and many patients, particularly those who had stopped smoking years ago or had never smoked, felt unjustly blamed for their illness ... Some patients concealed their illness, which sometimes had adverse financial consequences or made it hard for them to gain support from other people ... A few patients worried that diagnosis, access to care, and research into lung cancer might be adversely affected by the stigma attached to the disease and those who smoke.”

Ten years later, not much has changed.

Two recent studies found an association between lung cancer stigma and [delayed diagnosis](#) and treatment. Another pointed out the profound effect stigma has had on research [funding](#) and quality of care, both with regard to physicians’ attitudes toward patients and patients’ attitudes toward themselves. A [fourth](#) compared lung cancer stigma with that of four other cancer types.

Not surprisingly, lung cancer beat all comers.

## ‘Nobody cares about lung cancer’

Patients, of course, don’t need studies to know they’re being treated like second-class citizens.

Stoll said she’s been repeatedly called out for smoking (she never smoked) and has even been told matter-of-factly by a newspaper editor—while trying to get publicity for a fundraiser—that “nobody cares about lung cancer.”

Lung cancer patient Sherry Stoll and her husband, Don. Courtesy of Sherry Stoll

“That was really hard to hear,” she said. “It’s very much a blame-the-victim mentality. I’m a nonsmoker but you almost feel like you have to defend yourself and say, ‘I have lung cancer but I didn’t smoke.’ But then when you do that, you feel like you’re setting yourself apart from those who did smoke.”

Janet Freeman-Daily, a retired aerospace systems engineer and metastatic lung cancer patient from Seattle, witnessed so much stigma after her diagnosis, she became a [patient advocate](#).

“There’s lots of educating to be done around lung cancer,” said the 59-year-old, who’s currently

involved in a clinical trial and has been NED (no evidence of disease) for two years. “I’ve been shocked by people I thought were relatively open-minded who’ve said to me, ‘If someone smokes, they deserve lung cancer.’ Yes, it’s healthier not to smoke, but it’s not a sin that warrants the death penalty.”

Unfortunately, even patients who are diagnosed with the disease sometimes feel that it does.

“[The stigma] affects patients very strongly,” she said. “I have two friends who knew heavy smokers who were diagnosed and they both said, ‘I deserved this’ and refused to get treatment.”

Freeman-Daily said the stigma also impacts how health care providers care for patients.

“I know of patients who were told by their doctors to get their affairs in order because they were stage 4, and those patients went and got tested and found they could take a [targeted therapy](#) and they’re doing fine,” she said. “Research shows that the stigma exists even among health care providers. There’s a certain amount of [nihilism](#). [It’s like] ‘What’s the point? Why bother? They’re just going to die.’”

## Shared stigma

Some researchers, like Dr. Janine Cataldo of the University of California, San Francisco School of Nursing, compare the stigma surrounding lung cancer to that surrounding HIV, where dying patients were, and in many cases still are, shunned and/or blamed for their own suffering.

“I think in some ways lung cancer patients do share the discrimination that HIV patients used to suffer,” said [Dr. Bernardo Goulart](#), a public health researcher and oncologist with Fred Hutchinson Cancer Research Center and its treatment arm, Seattle Cancer Care Alliance. “People in the community will look at a patient with lung cancer and say, ‘You made poor choices in your life. You deserve less.’ That’s the attitude patients with lung cancer face.”

But Goulart said there’s a fundamental difference between the two groups.

HIV patients are often younger and tend to live longer, at least since lifesaving treatments have become available. As a result, they’re better able to advocate for themselves, particularly with regard to research funding. Over the last few decades, that advocacy has resulted in significant progress in HIV treatment.

“Lung cancer is different,” said Goulart. “These people are older, poorer and they live shorter lives. They have had much less power to advocate for themselves, and as a consequence, research for lung cancer has remained disproportionately low compared to HIV and especially low when compared with other cancers.”

According to federal research [funding statistics](#), lung cancer received about \$1,400 per cancer death in 2012, as compared to breast cancer, which received more than \$26,000 per cancer

death; prostate cancer, which got about \$13,500 and colorectal, which netted \$6,850.

Freeman-Daily, who is determined to raise awareness about the disease “in the time I have left,” said she understands that “there’s a certain sense that it’s a tough nut to crack” and that people may want to spend money where they can really make a difference.

But she thinks there’s more to it than that.

“People think, ‘Why should I spend money on something people did to themselves?’” she said.

## The struggle to quit smoking

Both Goulart and Dr. Jonathan Bricker, a psychologist and smoking cessation researcher at Fred Hutch, point out that for many people, the decision to smoke isn’t always a clear cut choice. “Most people interpret lung cancer as a self-inflicted disease when in reality, the decision to smoke is not an individual decision,” said Goulart. “It’s influenced by many other societal, cultural and economic factors. We know that individuals from a lower socioeconomic status are more likely to smoke than those of higher economic status. And individuals living in poor areas are more likely to smoke. And then there are the addictive properties of tobacco.”

Bricker, the force behind an effective new smoking cessation program [webquit.org](http://webquit.org), said most people start smoking in their teens and are soon addicted.

“Once their body develops a dependence on nicotine, they don’t have much control over the behavior anymore,” he said. “Nicotine is more addictive than alcohol and as difficult to stop as heroin. Once you’re hooked you don’t have a lot of control without some kind of behavioral or pharmacological intervention.”

Despite this intractable addiction, smokers and former smokers receive little support or compassion after receiving a lung cancer diagnosis. Those who have never smoked are snubbed as well, deemed guilty by association.

Why do people do this?

“It’s a way for people to avoid their own discomfort about someone else’s suffering,” said Bricker. “It’s a way to distance themselves. This is a highly stigmatized solid tumor and people are not getting the support they need. There’s a real lack of awareness about the causes of lung cancer and a lack of compassion for the struggle people have trying to stop their addiction. It’s really unfortunate and a very judgmental way of looking at lung cancer patients.”

The pervasive shame and blame is also doing real harm to patients, said Goulart.

“They may take more time to seek care for a disease they feel guilty about acquiring in the first place,” he said. “And they’re less willing to advocate for themselves. They feel shame about

having a disease they think they caused themselves. Besides physical symptoms, patients are dealing with guilt and shame at the same time. It makes for a harder process for these people.”

## Singled out

The truly ironic part is that lung cancer is just one of many diseases caused by smoking.

Smoking and tobacco use also lead to cancers of the esophagus, stomach, liver, pancreas, kidney, bladder, uterus, cervix, colon and ovaries. Much like obesity, the habit is also behind an ever-growing [list](#) of major diseases.

“I can’t tell you how many times I’ve heard of a family member who has lung cancer and the next thing out of someone’s mouth is, ‘They smoked—duh,’” said Stoll. “They’re saying they deserved it. If you go to McDonald’s every day and have a heart attack, is someone going to say you deserved it? Or if you gain a bunch of weight and get breast cancer, are they going to say, ‘You deserve it because you got fat?’ Nobody’s going to say that to you.”

The bottom line, say patients, researchers and advocacy groups like [Lung Cancer Alliance](#), [LCSMchat.com](#) and the American Lung Association’s [LUNG FORCE](#): Anyone with lungs can be diagnosed with lung cancer.

“People don’t realize that worldwide, 25 percent of lung cancer patients never smoked,” said Freeman-Daily. “The only thing I ever smoked was salmon.”

*\*Sherry Stoll died August 21, 2015, at the age of 54. In addition to raising awareness about the stigma that surrounds lung cancer, her nonprofit, [We Wish](#), has raised more than \$20,000 to fund research into the genetic mutation that triggered her disease.*

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