

How to Solve Lung Cancer's Catch-22

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Stigma as Deadly as the Disease

Editor's Note: *Lung cancer is the number-one cancer killer but it gets little respect in terms of research dollars and the public's attitude toward the disease. Medscape recently spoke to Linda Wenger, Executive Director of Uniting Against Lung Cancer, to talk about the issues faced by lung cancer patients and their advocates.*

Medscape: A study presented at the annual meeting of the American Society of Clinical Oncology documented that lung cancer carries a stigma that other cancers do not.^[1] Why are there negative attitudes toward lung cancer patients?



Linda Wenger

Ms. Wenger: Certainly one reason is the excellent job that the smoking cessation organizations have done. You see all these advertisements and TV commercials that vilify the smoker; I think the general public looks at smoking as a vice, as a weakness. Because most people associate lung cancer with smoking, they have a negative attitude toward lung cancer patients. Even the medical profession, in many ways, views lung cancer as a self-induced smoker's disease, and if *that* population isn't as enlightened as it could be, you certainly can't expect the general public to understand.

Medscape: Other diseases, such as heart disease and diabetes, are self-induced to some extent, but there is little or no stigma associated with them. In what ways does the situation with lung cancer differ?

Ms. Wenger: There have been campaigns against obesity and other causes of illness, but smoking has really become vilified, and that stigma affects not just the lung cancer patient but also the caregiver and the families; everybody carries that burden. There is just not the support system or outpouring of empathy for these patients and for their families who are caring for them that other cancer patients and their families receive. Think of how few champions there are for lung cancer. Most families of celebrities who have died of lung cancer won't admit it. They have even been known to say that they don't want their loved one's legacy to be associated with lung cancer because of the negative connotation.

Medscape: Despite the efforts of organizations such as yours, there seems to be only a limited support system in lung cancer. How do you explain this?

Ms. Wenger: One reason is that there are so few lung cancer survivors. A survivor population can champion a cause and serve as living reminders that people can beat the disease. We just don't have them in lung cancer. The 5-year survival rate is only 15% to 16%, and that hasn't changed since the 1970s. The medical community has certainly found ways to help people live 1 to 2 years longer, but they have not increased that 5-year survival rate.

Lung Cancer Research Grossly Underfunded

Medscape: Yet, it's important to note that a significant number of lung cancer patients are nonsmokers, and some have never smoked.

Ms. Wenger: Nonsmokers represent 2 groups: the never-smokers and the former smokers who have been able to quit. Many people who have been diagnosed with lung cancer quit smoking 20 or 30 years ago. These groups constitute a growing percentage of cases. We see more and more people who quit smoking, or who never smoked at all, who are diagnosed with lung cancer, and we don't know all the reasons.

We know that for some people there is a genetic mutation that occurs -- certainly in the never-smokers we see that -- with the discovery of the EGFR mutation, the ALK mutation, and others. Women comprise a larger percentage of this population and we don't know why. We don't know whether estrogen is involved, but that is why it is so crucial that we get more funding for research -- so we can answer these questions.

Our organization was founded in the memory of Joan Scarangelo, a never-smoker who died at 47 after a 9-month battle with lung cancer. Her mother had died of lung cancer 20 years -- to the month -- before. The family couldn't understand why there were no new treatment options over this time period. They created Joan's Legacy. It's now known as Uniting Against Lung Cancer, but our mission remains the same: to find a cure through scientific research.

Medscape: In terms of research dollars, how does lung cancer compare with other areas of cancer research?

Ms. Wenger: Lung cancer is disproportionately underfunded. The statistics of research dollars going to lung cancer compared with other cancers are very telling: In 2012, the federal government spent a little over \$21,000 per breast cancer death on research and about \$1400 per lung cancer death.

Medscape: That is shocking.

Stigma is the reason why the will for funding is just not there

Ms. Wenger: It is especially shocking because lung cancer is the number-one cancer killer, and this year we will lose more people to lung cancer than to the next 4 cancers combined. Even if you eliminate smoking-related deaths, lung cancer would still be the sixth most prevalent cancer. Given these statistics, the amount spent on lung cancer research doesn't make any sense.

I definitely believe that stigma is the reason why the will for funding is just not there. The corporate world has not yet stood up for lung cancer the way they have so marvelously for breast cancer. The

awareness and the monies raised for breast cancer have been just amazing and have made a huge difference for patients. We just don't have that in lung cancer.

Never-smoker: 'Cigarettes Are Going to Kill Me'

Medscape: Could you tell me about the scope of research funded by your organization?

Ms. Wenger: Since 2003 we have given out grants in the amount of \$10 million that go to scientific investigators at all levels: young investigators, post-docs, and senior investigators. A measure of our success is that our grantees have received over \$55 million in follow-on funding from sources like the National Cancer Institute and the National Institutes of Health. We have world-renowned lung cancer specialists on our medical committee who advise us on and review our grant applications. We get close to 200 grant applications and we award between 10 and 15 a year.

We have also been very successful in giving researchers the seed money to get their studies up and running, helping them get the data that they need for those larger grants. This is an area of real unmet need. It is very difficult, especially in lung cancer, to get that kind of money and many of our former grantees are now running their own labs.

Medscape: What other initiatives does Uniting Against Lung Cancer undertake to support the lung cancer community?

Ms. Wenger: Our signature event is a kite fly. We call it Kites for a Cure®. People come to a beach or park and decorate white kites with their messages of hope or memory. We do this to bring communities of people together to remember loved ones or support loved ones who are battling the disease. We spread the word that anyone can get lung cancer. We think that is a very important message and that these families and patients are deserving of our support no matter how they got lung cancer. There is just tremendous isolation for these families.

Medscape: What else is needed for lung cancer to become a higher priority in the public's eye?

Ms. Wenger: If we had the backing of the corporate world, of consumer companies that have tremendous ability to reach out to people and change perceptions, we think that would make a huge difference in terms of attitudes, and that would lead, we believe, to more funding. As more people begin living longer with lung cancer, and when we have more champions, I think it will help to change perceptions. It is a catch-22: We need the money to help lung cancer patients live longer, but it is hard to raise the money for research when patients don't live very long.

A good friend to our organization was diagnosed 3 years ago. She had been through quite a number of different treatments and had been quoted as saying time after time, "I never smoked, but cigarettes are going to kill me." She lost her battle with lung cancer several weeks ago.

References

1. Schiller JH, Bowden CJ, Mills J, et al. Explicit and implicit attitudes toward lung cancer (LC) relative to breast cancer (BC). Program and abstracts of the 2013 Annual Meeting of the American Society of Clinical Oncology; May 31-June 4, 2013; Chicago, Illinois. Abstract 8017.

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