Study Aims to Reduce Lung Cancer Stigma by Teaching Health Professionals Empathy

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For people with a history of smoking, a diagnosis of lung cancer can cause feelings of guilt and shame due to the stigma that's often associated with the disease. This stigma can hinder open communication between patients and health care providers and hinder patients' use of tobacco cessation counseling. Researchers at Memorial Sloan Kettering Cancer Center have developed a training program to help health care providers reduce lung cancer–related stigma. In this interview, the trial's leaders, Smita Banerjee, Ph.D., a behavioral scientist, and Jamie Ostroff, Ph.D., a psychologist, discuss the impact of stigma on people with lung cancer and an NCI-supported clinical trial that's evaluating the training program.

To begin, can you explain what you mean by stigma?

Dr. Banerjee: A classic definition of stigma is a mark of disgrace that sets individuals apart from others. In our research, we define stigma as a negative appraisal by others that can be attributed to a lung cancer diagnosis and internalized by the individual with lung cancer.

How commonly do people with lung cancer experience stigma?

Dr. Ostroff: In surveys, nearly all people with lung cancer say they have experienced stigma from doctors or acquaintances. And almost half of those with lung cancer say they have experienced stigma during visits with providers, including during routine smoking history assessments.

Dr. Banerjee: During these conversations, a patient may already be feeling guilty for engaging in a certain behavior and putting their family through the experience of caring for a loved one with cancer. Health care providers sometimes amplify a patient's feelings of shame and guilt through comments that are made without any intention of harming the patient, such as "You smoked for 20 years! What were you expecting?" or "You brought this on yourself." Even facial expressions can convey a negative message.

What are some of the harms that stigma can cause?

Dr. Ostroff: Research shows that stigma can contribute to people with lung cancer experiencing depression, withdrawing from friends and family, and refusing to get any help with tobacco cessation. Stigma can also make some people reluctant to share their diagnosis with friends and family, because they don't want to be lectured about smoking. This is unfortunate because if people don't share a diagnosis of lung cancer, they may not receive the social support that we know is so essential for all patients who are diagnosed with cancer.

Are there some unexpected consequences of lung cancer stigma?

Dr. Ostroff: As advances in lung cancer care have accelerated, we are now seeing an expanding group of lung cancer patient advocates. In many cases, these advocates are individuals who have not struggled with tobacco dependence. We think that stigma may be dividing the advocate community by contributing to an "othering" of people who smoke or have smoked.

What led you to develop the lung cancer training for health care providers?

Dr. Banerjee: We know that smoking is the leading preventable cause of lung cancer and 13 other cancers, as well as of countless chronic medical conditions. Advocates have been urging us to communicate about the importance of reducing smoking in ways that show compassion, respect, and support for individuals struggling with nicotine or tobacco addiction. We credit advocates with bringing this research problem to our attention.

Can you tell us about the trial?

Dr. Ostroff: Building on our previous studies, the training offers strategies to help health care providers communicate effectively with people who have a smoking history without using stigmatizing language. Sixteen sites nationwide will test what we call the Empathic Communication Skills training in a randomized trial.

The training is done virtually. Participants can practice skills in small groups with actors playing the roles of patients or caregivers. Trained facilitators provide tailored feedback. For health care providers, empathic communication involves conveying an understanding of a patient's perspective. This might mean encouraging people to express their feelings while also acknowledging and validating these feelings.

Dr. Banerjee: The role-plays are reminiscent of a standard part of medical education called Observed Structured Clinical Examination (OSCE), which is a way to evaluate a student's clinical skills in a simulated medical environment. We think it's important to emphasize that we're not providing a script for health care providers; rather, we are giving them a blueprint for engaging with patients, and it's up to each person to develop approaches that work for them and their patients.

How will you assess the success of the trial?

Dr. Ostroff: We will establish the success of the trial by evaluating the impact of Empathic Communication Skills training on health care providers' uptake of communication and empathy skills. We will also examine patient responses about their perceptions of lung cancer stigma and satisfaction with care.

Dr. Banerjee: Our hypothesis is that clinicians who are trained in empathic communication skills will be better able to engage with patients—and ask them about their smoking history—in a way that increases the likelihood that patients will participate in tobacco cessation programs. Clinicians are busy. They need evidence-based guidance regarding best practices for taking a smoking history, and we hope our training can help meet that need.

Is there a take-home message about communication between health care providers and people with lung cancer who have a history of smoking?

Dr. Banerjee: This trial is part of a national and even international movement to change the conversation around lung cancer. We know that words matter, and they matter to our patients. When stigma enters the medical consultation room, it can interfere with health care providers' ability to provide the recommended cancer care.

Dr. Ostroff: Taking a smoking history really does not need to be a painful medical procedure. We believe that learning certain communication skills can improve that experience and ultimately people's health.

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