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Original Research

LUNG CANCER

What Do You Mean, a Spot?

A Qualitative Analysis of Patients' Reactions to Discussions With Their Physicians About Pulmonary Nodules

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Background: **More than 150,000 Americans each year are found to have a pulmonary nodule. Even more will be affected following the publication of the National Lung Screening Trial. Patient-doctor communication about pulmonary nodules can be challenging. Although most nodules are benign, it may take 2 to 3 years to rule out cancer. We sought to characterize patients' perceptions of communication with their providers about pulmonary nodules.**

Methods: **We conducted four focus groups at two sites with 22 adults with an indeterminate pulmonary nodule. Transcripts were analyzed using principles of grounded theory.**

Results: **Patients described conversations with 53 different providers about the pulmonary nodule. Almost all patients immediately assumed that they had cancer when first told about the nodule. Some whose providers did not discuss the actual cancer risk or explain the evaluation plan experienced confusion and distress that sometimes lasted for months. Patients were frustrated when their providers did not address their concerns about cancer or potential adverse effects of surveillance (eg, prolonged uncertainty, radiation exposure), which in some cases led to poor adherence to evaluation plans. Patients found it helpful when physicians used lay terms, showed the CT image, and quantified cancer risk. By contrast, patients resented medical jargon and dismissive language.**

Conclusions: **Patients commonly assume that a pulmonary nodule means cancer. What providers tell (or do not tell) patients about their cancer risk and the evaluation plan can strongly influence patients' perceptions of the nodule and related distress. We describe simple communication strategies that may help patients to come to terms with an indeterminate pulmonary nodule.**

CHEST 2013; 143(3):672–677

Pulmonary nodules are common, with an estimated 150,000 new cases annually in the United States.[1] After publication of the results of the National Lung Screening Trial,[2] implementation of lung cancer screening with chest CT imaging will lead to the identification of even more nodules.[3] Fortunately, most are benign. Given the potential complications of biopsy[4] and low likelihood of cancer for most nodules,[5] most patients are managed with radiographic surveillance; if there is no growth over 2 years, the nodule is presumed benign.[6,7]

Discussing a pulmonary nodule with patients presents challenges. Ideally, providers should indicate why the nodule requires evaluation (to rule out cancer) without causing undue distress. Because most nodules are incidentally detected, providers must explain—and patients must digest—not only the finding of a nodule but also the results relating to the primary indication for the test. Finally, providers and patients should review the pros and cons of evaluation options and agree on a plan, ideally through shared decision-making.[7,8] All this must fit into the typical 15- to 20-min office visit or even through a brief phone call.

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Although the way cancer diagnoses are delivered is known to affect patient quality of life and adherence to subsequent care,[9,10] the more common situation of what providers say about possibly malignant lung nodules has not been described. We conducted a qualitative study of patient perceptions of provider-patient communication about a lung nodule in order to inform and improve these discussions.

Materials and Methods

We recruited participants from Boston Medical Center (which serves a racially diverse, economically disadvantaged urban population) and Dartmouth-Hitchcock Medical Center (a referral center for a rural population of mixed socioeconomic status). We identified English-speaking adults with an indeterminate pulmonary nodule by soliciting names from pulmonary and primary-care providers, reviewing referrals to pulmonary clinics, and searching problem lists and CT imaging reports (e-Table 1). Eligible patients were undergoing evaluation to rule out lung cancer. We invited patients to a 2-h focus group to discuss their experiences with a pulmonary nodule, offering a $40 gift card. Each site's institutional review board approved this study, and all participants provided informed consent.

We conducted four focus groups (two per site) with 22 patients. Facilitators (R. S. W., a pulmonologist, and J. A. C., a medical sociologist) invited patients to describe their experiences in their own words. Discussions covered topics in prespecified domains (e-Table 2) derived from clinical experience and a literature review and topics raised by participants. Discussions were audio recorded and transcribed.

The analysis centered on characterizing the influence of physician-patient communication on patient understanding of the nodule and related distress and identifying communication elements that helped or hindered patients in coming to terms with the diagnosis. Using grounded theory methodology,[11,12] we developed and revised preliminary thematic content categories through close readings of transcripts, which were then systematically coded with category labels. Repeated comparisons of passages within and between categories, within and between participants, and within and between groups resulted in the iterative formulation of thematic summaries that were critically reviewed by the team. When differing interpretations arose, we discussed relevant sections of transcripts until consensus was achieved. We reached thematic saturation after four focus groups.

Results

Patients described conversations about their nodule with 53 providers from academic and community practices, including primary-care providers, pulmonologists, and thoracic surgeons. The involvement of multiple clinicians most often stemmed from referral by the provider first faced with an incidental nodule (eg, ED physician) to the primary-care provider, often followed by a second referral to a pulmonologist. Table 1 shows the characteristics of the study patients.

The Impact of Disclosure

Virtually all participants reported an immediate concern about cancer upon learning of the nodule: "What are we ruling out if it's not cancer?...when they say nodules or spots on your lungs, it's just the first thing you think of. What other options are there?" (patient 11). Some went farther, immediately worrying about chemotherapy or death: "My first thought was, 'which one's going to get me first? Will I die of the emphysema, or will I die of cancer?'" (patient 12). There was no association between actual cancer risk (calculated quantitatively[13]) and patient qualitative risk perceptions; even those with tiny nodules feared that they had cancer.

Because most participants assumed that a nodule meant cancer, it is not surprising that many described learning about the nodule as traumatic, with effects that sometimes lasted for months:

> My kidney doctor calls me up and says, "Oh by the way, we found a tumor on your lungs."…They didn't even know what it was, but it was just the way [he] came out and said it. I was devastated.…I bawled through Christmas. (patient 13)

By contrast, others found their physicians' explanation reassuring:

> [I said,] "What do you mean, a spot? What are you talking about?" He said, "Yeah, but try not to panic."…He described with a pen and a paper and showed me just how big it was on the scan and told me just what it entailed. (patient 7)

Patient-Important Communication Elements

Addressing Cancer Risk: Most patients preferred simple language, including acknowledgment of the possibility of cancer: "Don't hide nothing.…Tell me the truth, tell me in my language, so I understand what you're saying" (patient 9). Many wanted an estimate of cancer risk in either in quantitative ("5%-10%") or qualitative ("unlikely") terms. In most cases, this information was reassuring because the physician's estimate was much lower than the patient's assumption.

Several participants said that their physicians never mentioned cancer. Only one patient openly preferred this strategy: "Whatever is going to happen will happen, and I don't want to know!" (patient 18). Others were

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Manuscript received April 28, 2012; revision accepted June 26, 2012.

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Funding/Support: This study is funded by a career development award from the National Cancer Institute [K07 CA138772]. Dr Gould is supported by the National Cancer Institute. Drs Wiener, Woloshin, Schwartz, and Clark receive salary support from the Department of Veterans Affairs.

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DOI: 10.1378/chest.12-1095