

Patients' Knowledge, Beliefs, and Distress Associated with Detection and Evaluation of Incidental Pulmonary Nodules for Cancer: Results from a Multicenter Survey



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ABSTRACT

Introduction: Pulmonary nodules are detected in more than 1 million Americans each year. Prior qualitative work suggests that the detection of incidental pulmonary nodules can be burdensome for patients, but whether these findings generalize to a broader sample of patients is unknown. We categorized patients' knowledge, beliefs, and distress associated with detection and evaluation of a pulmonary nodule, as well as their impressions of clinician communication.

Methods: We administered a cross-sectional survey to adults with an incidental pulmonary nodule who were recruited from a rural medical center, an urban safety net hospital, and a Veterans Affairs hospital.

Results: Of the 490 individuals mailed surveys, 244 (50%) responded. Median nodule size was 7 mm, mean patient age was 67 years, 29% of respondents were female, and 86% were white. A quarter of the respondents (26%) reported clinically significant distress related to their nodule, our primary outcome, as measured by the Impact of Event Scale. Patients reported multiple concerns, including uncertainty about the nodule's cause (78%), the possibility of cancer (73%), and the possible need for surgery (64%). Only 25% of patients accurately estimated their lung cancer risk (within 15% of their actual risk); overall, there was no correlation between perceived and actual risk ($r = -0.007$, $p = 0.93$). The 23% of patients who did receive information on cancer risk from their provider were more likely to find this information reassuring (16%) than scary (7%).

Conclusion: A quarter of patients with incidental pulmonary nodules experienced clinically significant distress. Knowledge about cancer risk and evaluation was poor. Clinician communication may help bridge knowledge gaps and alleviate distress in some patients.

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Keywords: Solitary pulmonary nodule; Lung neoplasm; Patient-centered outcomes research; Survey; Communication; Health behavior

Introduction

More than 1.5 million Americans are found to have a new pulmonary nodule each year through incidental detection, and these numbers are expected to rise further with adoption of lung cancer screening.^{1,2} When

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a nodule is detected, clinicians must convey to the patient what the nodule is (i.e., the possibility of cancer, which is less than 5% for most patients) and how the nodule will be evaluated.³ For most patients, evaluation will entail a 2-year course of radiographic surveillance to ensure that the nodule is not enlarging; guidelines suggest reserving invasive procedures for those with a higher risk for cancer.^{4–6}

Given how often pulmonary nodules are found, it is important that clinicians understand the experience and concerns of patients with pulmonary nodules and be prepared to discuss them.^{3,7–9} Yet, how the experience of nodule detection and evaluation affects patients is not entirely clear. Qualitative studies and a single-center survey of patients with incidentally detected nodules suggest that detection and evaluation can lead to distress and reduced quality of life in some cases.^{3,8–10} However, whether these results are generalizable is unknown. Recognizing the increasing emphasis on patient-centered care and the growing numbers of patients with pulmonary nodules, the American Thoracic Society recently called for more research to explore the impact of nodule detection on patients.¹¹

We sought to more fully characterize the psychosocial impact of nodule detection and evaluation with a survey of patients with incidental pulmonary nodules managed at three diverse clinical sites in the northeastern United States. We hypothesized that a subset of patients would report substantial nodule-related distress and that misperceptions regarding pulmonary nodules and their evaluation would be common.

Materials and Methods

All study procedures were approved by the institutional review boards at the three sites.

Study Population

Participants were recruited from three diverse sites: Boston Medical Center, an inner-city safety net medical center; Dartmouth-Hitchcock Medical Center (DHMC), a tertiary care center in a rural setting; and the Veterans Affairs (VA) Boston Healthcare System, a large urban VA hospital. Eligible participants were English-speaking adults (between the ages of 18 and 89 years) who had been found to have a pulmonary nodule smaller than 3 cm within the 3 years before survey administration. Eligible participants were identified through three methods: (1) computerized search of chest imaging reports for terms such as *pulmonary nodule*; (2) computerized search of clinicians' problem lists for the term *pulmonary nodule*; and (3) manual review of a clinical registry of patients with pulmonary nodules.

Survey Instrument

We designed a self-administered questionnaire to cover topics in six domains: (1) nodule-specific knowledge, (2) nodule-specific distress, (3) health behavior, (4) nodule management preferences, (5) patient-clinician communication, and (6) patient characteristics. Within these domains we identified the issues of greatest relevance to patients through a series of four focus groups at two sites (Boston Medical Center and DHMC) and developed survey items to probe these issues.^{3,9} The draft survey instrument was tested for content, clarity, and comprehensibility through a series of pilot tests. First, we sought feedback from three experts on survey research and 13 content experts from two medical centers (eight pulmonologists and five primary care providers). Next, we administered the survey to a convenience sample of 13 patients with incidentally detected pulmonary nodules who had been seen in the DHMC pulmonary clinic. Finally, we performed in-depth cognitive interviews with three patients with pulmonary nodules. The survey was iteratively revised in response to feedback from each of these steps. The final survey instrument consisted of 46 items and included both validated scales and novel questions (see Survey, [Supplementary Digital Content 1](#), for the complete survey questions).^{12,13}

Survey Administration

We mailed the survey to eligible participants between July 2011 and December 2012. Mailed reminders regarding survey completion were sent after weeks 2 and 4. Participants who returned surveys received a small incentive (a \$10–\$15 gift card).

Outcome Measures

Our primary outcome was nodule-specific distress, as determined on the basis of Impact of Event Scale, a validated 15-item measure of distress related to a specific event (i.e., nodule detection) that is composed of two subscales: intrusion (intrusive thoughts) and avoidance (actively staying away from reminders of the nodule).^{13,14} We selected this measure to allow direct comparisons with other studies of patients with incidentally detected and screen-detected nodules.^{10,15,16} Scores range from 0 to 75, with higher scores indicating more distress. As in prior studies of cancer-related distress,^{17–20} we used the recommended categories of normal (score 0–8) or mild (9–25), moderate (26–43), or severe (44–75) distress, with clinically significant distress defined as moderate or severe (score ≥ 26).²¹

We measured perceived lung cancer risk using a simple visual analogue scale that ranged from 0 in 100 (labeled as “0%, no chance”) to 100 in 100 (“100%

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