ORIGINAL RESEARCH

# What the Heck Is a "Nodule"?

## A Qualitative Study of Veterans with Pulmonary Nodules

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## Abstract

**Rationale:** Every year, hundreds of thousands of patients are diagnosed with incidentally detected pulmonary nodules, and if lung cancer screening is widely implemented, thousands more will be identified. The psychosocial outcomes associated with incidental nodule detection in general practice settings are virtually unknown.

**Objectives:** The purpose of this study was to explore the experiences of patients with incidentally diagnosed pulmonary nodules.

**Methods:** We conducted qualitative interviews of 19 veterans with incidentally detected pulmonary nodules. We used qualitative description for the analysis, focusing on patients' information exchange and other communication behaviors with their clinicians.

**Measurements and Main Results:** The patients were cared for by primary care clinicians and had small nodules that were unlikely to be malignant. Patients did not understand the term "nodule" although they knew it was related to cancer. They also did not understand the follow-up plan and most were unable to obtain better information from their clinician or other sources. Most patients experienced nodule-related distress that was usually mild, although sometimes severe. This distress was sometimes mitigated by patients' confidence in their clinician. Most patients wanted more and better information about their nodule.

**Conclusions:** Veterans from one hospital have little understanding of what nodules are, the likelihood of malignancy, and the follow-up plan. Their reaction to this knowledge deficit is variable and is likely related to preferred communication behaviors with their clinician. Evaluating communication in other settings is important to confirm these findings and to refine mechanisms to improve patient-centered care for those with incidentally detected pulmonary nodules.

**Keywords:** pulmonary nodule; lung cancer; patient-centered outcomes; communication

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Hundreds of thousands of patients are diagnosed every year with incidental pulmonary nodules (1–3) and this number will likely increase, based on recommendations to consider screening asymptomatic smokers and former smokers by chest computed tomography (CT) (4–7). These recommendations are based largely on the National Lung Screening Trial, which demonstrated that screening decreased lung cancer deaths but also had a high rate of false positive results, usually because of pulmonary nodule detection (8).

Professional societies have called for research to better characterize the experiences of patients with nodules (4). Overall, in mostly European screening trials, subjects with nodules report a short-term increase in distress but no change in health-related quality of life (9–13). One study found that patients with incidental pulmonary nodules experienced significant distress after the diagnosis (14). It remains important to evaluate patients in multiple clinical settings because results from subjects in screening are likely not generalizable (15).

We explored the experiences of patients with incidentally diagnosed pulmonary nodules. We were particularly interested in knowledge about the nodule and the influence of clinician communication on patient-centered outcomes.

## Methods

### Overview and Setting

We conducted a qualitative study at the Portland Veterans Affairs Medical Center (PVAMC, Portland, OR), an academically affiliated hospital with outlying primary care clinics, among patients with an incidentally detected (not from screening) nodule. At the PVAMC, thoracic radiology images with nodules are electronically flagged (3). Primary care providers (PCPs) are usually responsible for notifying the patient and determining the evaluation without guidance from pulmonologists.

Medical records from patients with nodules were reviewed. Asymptomatic patients with a plan to obtain nonurgent imaging follow-up were potentially eligible. After approval from the PCP and mental health clinician (if relevant), we contacted the patient by mail to participate. The Institutional Review Board of the PVAMC approved this study and all patients provided signed informed consent.

Patients were community-dwelling adults with at least one nodule detected during routine care. We excluded patients who scored less than 17/30 on the Saint Louis University Mental Status Examination (16), who resided in skilled nursing care facilities, were diagnosed with psychotic or cognitive disorders, had a terminal illness, or had severe hearing impairment. Participants were interviewed by C.G.S., a pulmonologist, and/or by L.G., a psychiatrist. Interviews were digitally recorded and transcribed. We recorded self-reported demographic and smoking characteristics and nodule characteristics based on the imaging report.

### Analysis

We used qualitative description (17), which allows comprehensive description of a patient's experience in everyday language with little dependence on interpretation or theorization (17). First, C.G.S., N.P., and L.G. reviewed, as a group, five completed patient transcripts to develop a codebook. The codes began with, and remained close to, the questions of the interview guide that explored the veterans' experience of receiving information about the nodule, concerns, understanding of the evaluation plan, comfort, satisfaction, understanding, desire for more information, and ideas on improving the lung nodule process. More conceptual "free codes" were also added for issues and concerns that arose in reading the first five interviews. After the initial codes were developed, two of the nvestigators, C.G.S. and L.G., independently reviewed and coded the original five transcripts. All three investigators reviewed, coded, and then discussed the same transcripts to identify codes that were unclear or were coded differently. We achieved more than our predetermined 80% level of agreement to show trustworthiness of these analyses. C.G.S. independently coded the remaining transcripts. L.G. separately reviewed and coded five of these transcripts to ensure consensus was maintained. We reached thematic saturation after 19 patients were interviewed. We used ATLAS.ti 6.2.27 (ATLAS.ti GmbH, Berlin, Germany) to organize the data.

## Results

The characteristics of the 19 participants are summarized in Table 1. All the patients had a plan to obtain follow-up imaging for their nodule(s) after the baseline interview and none have been diagnosed with lung cancer at the time of data analysis. Patients were cared for by primary care providers and all had small nodules with a low risk of malignancy. The average time from diagnosis to interview was 154 days (SD 145), which did not seem to influence the patients' responses.

### Receipt of Information about the Pulmonary Nodule

Most veterans received a notification letter from their PCP. The letters often included a "cut and paste" version from the impression of the imaging study plus a note about the subsequent plan. Patients were perplexed because they did not understand the language, felt it was written in jargon, and did not understand the implications of the finding. Almost universally, they found the term "nodule" baffling (Table 2). As one patient described the notification, "*…basically the only thing I received was a piece of mail that was—as far as I was concerned it should have been in Latin because it didn't really explain anything at all that made any sense to me*" (Veteran A). The minority who spoke with their clinician regarding the nodule seemed similarly puzzled. Veterans who ventured

**Table 1.** Cohort characteristics

| Characteristic | Statistics |
|---|---|
| Age (yr), mean (SD) | 66 (11) |
| Male, n (%) | 18 (95%) |
| Race/ethnicity, n (%) | |
| White | 17 (94%) |
| Smoking status, n (%) | |
| Current smoker | 4 (21%) |
| Former smoker | 10 (53%) |
| Never-smoker | 5 (26%) |
| Education, n (%) | |
| High school or less | 7 (39%) |
| Largest nodule size (in diameter), mean (SD) | 5 mm (3 mm) |
| Time from nodule detection to baseline interview, mean (SD) (median) | 154 d (145) (121) |
| Type of physician caring for nodule | |
| Primary care provider | 19 (100%) |
| Attending | 15 (79%) |
| Nurse practitioner | 3 (16%) |
| Physician assistant | 1 (5%) |

Percents are of nonmissing information.

**Table 2.** Veterans' inadequate knowledge of pulmonary nodules

| |
|---|
| "Holy crap, what the heck is a lung nodule?" (Veteran Q) |
| "Well, what the hell is a lung nodule? And I still don't know.…Where did it come from, why is it there, is it cancerous?" (Veteran G) |
| "I don't even know what a lung nodule is. I don't know if it's like a nice way of saying a tumor or some unknown blobby mass." (Veteran H) |
| "Well, I'd like to find out what a "nodule" is. What are the odds of it turning malignant? What's the different between a nodule and a tumor?" (Veteran B) |
| "What are nodules? How do you get them? Where do they come from?" (Veteran M) |
| "I looked up 'nodule' in a dictionary and it says 'a knob' so that doesn't tell me anything. Is it something big, small? What does it do to affect your breathing? But when you don't know anything, you're kind of in the dark." (Veteran E) |
| "First of all, what is a nodule? I don't know what—just a dark spot on X-rays?" (Veteran K) |
| "It's kind of—hearing 'nodule' it's like in that movie *Armageddon* when they talked about 'anomalies.' Stop with this 'anomaly' horse-shit. Tell me what it really is. Stop with the 'nodule' thing. What's really going on? It doesn't mean anything. I don't even know what a 'nodule' is. A spot? A pocket of weirdness?" (Veteran I) |

a guess at what a nodule might be used such terms as "*spot*" (Veteran C), "*a little bump on my lung*" (Veteran D), "*knob*" (Veteran E), "*wart*" (Veteran F), "*growth*" (Veteran G), "*small, almost tumor-like thing*" or "*tumor or blobby mass*" (Veteran H), "*a thing on my lung*" (Veteran I), and a "*pocket of weirdness*" (Veteran I).

Patients rarely understood the follow-up plan, often had only a vague sense of when follow-up was scheduled, and did not understand the role of imaging surveillance. One patient, when asked what the follow-up plan entailed, replied, "*I would like to know. I don't—you know if I knew more about them* [the nodules] *then I guess I could make a plan but I don't know*" (Veteran F). Indeed, some patients did not understand the purpose for further radiologic studies. Their responses suggested a lack of understanding that the nodule was likely benign and conveyed the perception that a dangerous situation was being ignored. "*Well, as far as I know there is no long-term plan. It's just like, 'We're gonna wait and see what's going to happen in 6 months or a year.' That's not a plan. That's avoiding the situation*" (Veteran A).

All the patients understood the nodule might be caused by lung cancer, despite seldom receiving information regarding the relationship between nodules and lung cancer. Although the letters rarely mentioned "lung cancer," patients thought about it: "*I think everybody does, you know if they hear they got something abnormal about them. Is it cancerous or noncancerous?*" (Veteran J). Regardless of whether they had specifically discussed this concern with a clinician, they reported concern about the possibility of cancer along with inadequate knowledge of the risk of malignancy.

Most patients did not have enough information to estimate the likelihood of malignancy. Some significantly overstated this risk. For instance, one patient reported the risk that of lung cancer was "*better than 50/50*" (Veteran B) whereas the calculated risk was 3% (18). Several patients correctly interpreted the interval of follow-up imaging as a surrogate for cancer risk although few discussed this aspect of surveillance with their PCP. They reasoned that if the risk of cancer was high, follow-up would be more prompt. For example, one patient reported, "*If* [the PCP] *said 'I'll see you in a month' I would think that there was something ominous*" (Veteran L).

### Obtaining More Information

It was rare that patients obtained better information, for multiple reasons: patients felt the clinician was unavailable, the system made it difficult to obtain information, outside resources provided unsatisfactory information, the nodule was one of many problems, they feared knowing more, or they took clues from their clinician about whether more information would help. Although notification letters encouraged questions, many patients perceived that attempting to obtain more information would be unsuccessful for one of three reasons: an inability to directly contact the clinician, support staff could not provide useful information, or the clinician would not be knowledgeable or have the time to adequately answer questions. As one of the few veterans who attempted to obtain more information reported: the PCP's "*assistant called me and she didn't answer any questions. It was like talking to my dog pretty much. I was trying to get some information out of her. And she's like, 'Why, I really can't discuss this with people, blah, blah, blah*'" (Veteran H).

Some believed the onus of providing more information should be on the PCP and not on the patient. One patient pointed out that the system was not well designed to answer questions not directly related to the chief complaint. "*VA has an in and out process. And I'd go in there with a cold, or something like that, and that's all they wanted to hear about*" (Veteran M).

Many patients sought information about the nodule from outside sources including clinicians they saw for unrelated problems, friends and family, the Internet, and the dictionary. Most patients still did not have adequate information after consulting outside references. The information they obtained was generally unsatisfactory and potentially misleading because patients often focused on the consequences of lung cancer rather than on the likelihood that a nodule was cancer. "*I tried to find out information about how serious lung cancer might be. What are the odds of living through it? How long am I allowed? Find out just what the term 'pulmonary nodule' might mean in reference to the size I was given…But again the Internet is a catch-as-catch-can, you can't always trust the information*" (Veteran A).

Some patients placed a low priority on improving their knowledge because the nodule was one of many problems, both medical and nonmedical. Patients cited active symptomatic medical problems that led them to rank information about the nodule as less important. For example, a patient said, "*Actually, I don't think I even asked* [the PCP] *about anything. I was more concerned with this pressure in my stomach there and that kept pushing against my lungs and making it a bit difficult to breathe and trying to figure out what that was. Because that I could feel. And that's what I wanted taken care of. And something that wasn't bothering me* [the nodule]*—forget it—I couldn't care less*" (Veteran D).

Some patients were fearful of what they might learn if they tried to get more information and discussed using active avoidance to cope with the knowledge about the nodule. "*Oh crap, here's something else that might come up and bite me in the ass someday and get me. I'm* [XX] *years old and just wish this hadn't come up and I'm going to try not to think about it for next year and put it out of my mind for a whole year. And as the time increased that I got past the results I more or less started to forget about it. And the more I didn't think* *about it, I did forget about it quite a bit*" (Veteran O). Another patient expressed a similar strategy of actively avoiding thinking about the nodule, "*Just the uncertainty of what it* [the nodule] *is. I try not to dwell on something that I don't know about*" (Veteran J).

Several veterans did not feel they needed more information. For some, this response seemed determined by their general outlook regarding medical problems. "*What can you do? You just go on day to day and that's good enough.… Well, there's nothing I can do about it. That's for certain. So why would I lose any sleep over it?*" (Veteran G). Many patients who were not concerned about the lack of information took cues from their PCP regarding this knowledge deficit. Some trusted the PCP to provide more information about the nodule if it was warranted or were explicitly told it was not a cause for worry. For instance, "*I had confidence in him* [the PCP] *and I figured if it was something that he was really worried about he would have done more about it. Even though it made me feel kind of iffy about stuff, I figured that he wasn't worried so I shouldn't be*" (Veteran C).

Other patients were less reassured by their clinician's recommendation not to worry. For example, one patient said, "*Yeah, I feel like I wasn't given very much information. I was just told not to worry about it. I wasn't sure what it was I wasn't supposed to worry about. He may have just assumed that I knew what a lung nodule was, I don't know*" (Veteran Q).

### Emotional Responses to Nodule

Veterans' emotional responses to the diagnosis were also variable (Table 3). Some expressed curiosity about the possible cause of the nodule but were not distressed. Others experienced mild distress but used active coping and attempted not to think about the nodule. Still others experienced pervasive worry and actively made attempts to cope with the negative impact. Terms used included "death sentence," "scary," and "shocking." Worry was mitigated for the sizable minority of patients who trusted their clinician to provide high-quality care. Related to our finding regarding information seeking, many of these patients seemed to take comfort in their clinician's implicit or explicit level of concern for a worrisome cause of the nodule (Table 4).

**Table 3.** Veterans' emotional reactions to pulmonary nodule diagnosis

| |
|---|
| **No Distress** |
| "Curious. I mean, what is it? I was just curious to find out what it is. I mean, nothing scary. I'm not worried about it. No, I don't worry about it. When it's time to go, it's time to go. I'm not worried about it." (Veteran K) |
| "So until it starts [to cause symptoms], I'm not going to worry about it." (Veteran D) |
| "No, I wasn't worried about it. All I know is that if there's anything to do to help it, I'm interesting in doing it." (Veteran S) |
| **Mild Distress** |
| "Na, I don't think about it every day, just every once in a while, or maybe when I go to bed at night or something I'll start thinking about it or something or….It's not a thing that it eats at me constantly. It's just once in awhile pops into my mind." (Veteran C) |
| "I am not consumed by it or plagued by it, it doesn't slow me down. It's just one of those things. If I do think of it I say, 'Well, I wish that wasn't there. Hope there's nothing there next time I come in.' And I continue on." (Veteran O) |
| "I don't think 'worried' is the right word. You know, I've got maladies all over. I mean, you can't worry about *stuff* [patient emphasis]. I just want more information now." (Veteran F) |
| **Moderate/Severe Distress** |
| "Well, like I said, there's family history in there, so pretty worried. I don't know what it turns into later or what it is and they didn't show me the picture. Just so, every once and a while I'll lay awake at night and stare up at the ceiling." (Veteran B) |
| "Basically I was devastated. I thought I had cancer. I called my son and my daughter-in-law and told them I needed to talk to them. You know, in Oregon they got assisted suicide, and there is no way am I gonna be like my mother. I do not want to get to that point.… But I would go the route of assisted suicide.“ (Veteran P) |
| "In the week since I found it? It has definitely made me evaluate things. Other than adding a humongous level of stress, it's put a lot of things on hold, major plans, just because I don't want to plan something and find out, 'Oh, gosh, guess what. It's what you think it is.' I'd say it has affected the quality (of life) I guess.…Probably went out and got plastered because I figure if I just make myself drunk enough I won't have to deal with it." (Veteran H) |
| "I didn't know what I was reading and so I didn't really have any information. But, generally speaking, I tend to think in dramatic terms so I thought, 'This is a death sentence.' Pretty much. Someone's telling me I'm going to die of lung cancer but no one's telling me, 'Oh it's going to kill you in 3 months' or 'You have 12 years to live' or anything like that. No information at all." (Veteran A) |

### Improving Information Exchange

All the patients said they were fairly to extremely satisfied with VA health care but had many ideas for improving the system. Their suggestions included providing more information about the nodule, the risk for lung cancer, a description of the follow-up plan, and signs and symptoms that should trigger them to contact their clinician (Table 5). They wanted information with less jargon, appointments to discuss the nodule, and view the image themselves. Finally, most patients reported they preferred the notification in person, as reported by one patient who said, "*You know, I wouldn't want to get that information over the phone. I would have wanted him to show me pictures, explain what it was, what's going on. I'm an 'information' kind of guy*" (Veteran I).

## Discussion

Our main finding was that patients found the term "nodule" mystifying, although they implicitly knew it was related to cancer. Having no reference for the term made it difficult for information to have meaning or to understand the evaluation plan. Most patients did not seek more information from their health care providers, citing multiple barriers. Most patients experienced at least mild nodule-related distress that was sometimes mitigated by their clinician.

Hundreds of thousands of patients are diagnosed with pulmonary nodules every year (1), and consideration of CT screening is now widely recommended (4–7). Coupled with the number of patients who undergo imaging studies (19–22), there will likely be an onslaught of patients with small pulmonary nodules. It is important to have a better understanding of information needs and the psychosocial consequences of nodule detection to provide patient-centered care (4). Our findings indicate that improved patient information is essential. At the core of this exchange will be plain language explanations of what nodules are, why they appear on imaging, the relationship of nodules to cancer, and the reasoning behind the extended approach to surveillance.

**Table 4.** Veterans' responses to their clinician's concerns about the pulmonary nodule

"Well she [primary care clinician] was reassuring in the sense she didn't think that there was anything to be concerned about." (Veteran L)

"I don't think he [primary care clinician] made a big deal out of it. And neither did I." (Veteran R)

"Well, it seemed like my doctor would be more concerned….She's a good doctor…because she would call me back if it was serious. She wouldn't just let me go." (Veteran N)

"Yeah I didn't know what that [the nodule] was so I didn't concern myself. I went on vacation anyhow. I feel OK. I feel fine. If it's something life-threatening or something like that, I'm sure I would have been notified…I trust the VA implicitly." (Veteran K)

"It didn't really dawn on me that it was important. I really didn't think anything of it. They didn't seem excited about it so I wasn't….Well, I felt if they didn't care about it, I didn't care about it." (Veteran F)

"They never gave me any reason to think that I should be concerned. They did say in there that they would follow up on this in maybe 6 more months. So I'll get another CT scan so they can compare apples to apples." (Veteran E)

"I've gotten good care. If it was something that was growing and my doctor would have said something and we would have discussed the best way to take care of it. We'll know after this next CAT scan whether it's growing or not. And if it isn't then we're doing everything fine. And if it's growing, well then we'll go from there." (Veteran D)

**Table 5.** Veterans' concerns regarding pulmonary nodule communication and possible solutions

| Concern | Possible Solutions |
|---|---|
| Inadequate understanding of nodule biology | Describe:<br>• Causes of nodules<br>• Risk of lung cancer<br>• Rationale for active imaging surveillance rather than biopsy |
| Use of jargon | Use:<br>• Plain and simple language<br>• Pictures |
| Notification by letter | Notify in person or via telephone |
| Inadequate knowledge of follow-up plan | Provide:<br>• Date of follow-up imaging study in writing |
| Inadequate knowledge of when to contact the primary care physician (PCP) | Provide:<br>• List of signs and symptoms that should prompt contact |
| Inability to contact PCP or ask clarifying questions | Provide alternative means of obtaining information:<br>• Written and/or online educational resources<br>• Electronic communication methods |

Although information is a core domain of patient-centered communication (23), our patients uniformly received inadequate information about the nodule. The relationship of information exchange and other communication behaviors with patient-centered outcomes is complex (24). Information exchange is associated with trust in the clinician (25) and risk perception is associated with quality of life, even after adjusting for clinicians' communication behaviors (26). Among veterans with lung disease, patient-reported clinician expertise, perhaps a surrogate for adequate information exchange, is associated with high-quality communication (27), which in turn is associated with patient-centered outcomes (28). Decreasing distress may be partly accomplished by providing more adequate knowledge, but education materials and decision aids may not be sufficient (29, 30). Thus, further research to clarify the associations between individual communication behaviors and patient-centered outcomes is required.

Wiener and colleagues described the consequences of incidental pulmonary nodule identification, using a qualitative analysis from focus groups of 22 nonveteran patients from two academic medical centers in the Northeast (14). Similar to our results, these patients were confused by the jargon used to describe the nodule and most had inadequate knowledge about the likelihood of its being malignant and of the follow-up plan. They also reported varying degrees of distress regarding the likelihood of malignancy. Patients in our study often felt reassured by the clinician's communication behaviors used to decrease distress, even when they had inadequate knowledge. Conversely, Wiener and colleagues found that patients who perceived their clinicians as dismissive of their concerns were sometimes offended. These are the only two studies to evaluate patient-centered communication for patients with nodules and include patients from substantially different settings. Further research, both qualitative and quantitative, is needed to confirm our findings that patient-centered communication behaviors may be inadequate for patients in other settings, such as those engaged in lung cancer screening. Our study will longitudinally monitor the patients during the process of nodule evaluation, which will allow further evaluation of patient–clinician communication over time.

There are limitations to our study. Although Wiener and colleagues reported similar results in a different setting, our study was conducted among mostly male, elderly veterans from the Pacific Northwest, so our results may not apply to patients in other settings. The time between the interview and nodule diagnosis was relatively prolonged, which might influence the level of expressed distress and knowledge. Our cohort likely suffers from a selection bias for patients with more knowledge and better communication because we recruited patients after permission from their PCP.

## Conclusions

Patients have little understanding of what nodules are, the likelihood of malignancy, and the follow-up plan. Their reaction to this knowledge deficit is variable and is likely related to preferred communication behaviors with their clinician, including the mode of notification. Evaluating communication in other settings is important to confirm these findings and refine mechanisms to improve patient-centered care for those with incidentally detected pulmonary nodules. ■

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