Primary Care Providers and a System Problem

A Qualitative Study of Clinicians Caring for Patients With Incidental Pulmonary Nodules

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BACKGROUND: As lung cancer screening with low-dose CT scanning is implemented, an increasing number of people will be diagnosed with pulmonary nodules. Primary care clinicians care for the vast majority of these patients, but their experiences with communication and managing distress in this population are not well understood.

METHODS: We conducted qualitative interviews of 15 primary care providers (PCPs) at two academic medical centers who care for patients with pulmonary nodules. We used qualitative description analysis, focusing on clinicians' information exchange and other communication behaviors.

RESULTS: Most PCPs believed they had inadequate information to counsel patients regarding lung nodules, although this information is desired. PCPs were concerned patients could "fall through the cracks" but did not have access to a reliable system to ensure follow-up adherence. They were limited by time, knowledge, and resources in providing the preferred level of care. Most PCPs did not discuss the specific risk a nodule was lung cancer, in part because they did not have ready access to this information. PCPs believed most patients did not have substantial distress as a result of nodule detection. Most PCPs did not include patients when making decisions about the follow-up plan.

CONCLUSIONS: PCPs often lack systemic resources to optimize patient-centered approaches when discussing incidental pulmonary nodules with patients. With the advent of lung cancer screening, pulmonologists can assist primary care colleagues by providing accurate information to counsel patients and assisting in managing conversations about the risk of cancer. Pulmonologists should support efforts to implement reliable systems to ensure adherence to follow-up.

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ABBREVIATIONS: BUMC = Boston University Medical Center; PCC = patient-centered communication; PCP = primary care provider; VA = Veterans Affairs; VAPORHCS = VA Portland Health Care System

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Incidental pulmonary nodules are frequently detected when patients undergo chest imaging.^{1,2} More patients with nodules will be detected, since lung cancer screening using low-dose CT scanning is now widely recommended and anticipated to increase.³⁻⁷

Although some patients enrolled in lung cancer screening trials have shown an increase in negative psychosocial outcomes such as distress and anxiety, findings are inconsistent.⁸⁻¹⁰ Among patients with incidentally detected nodules in routine clinical settings, distress seems to be common and occasionally severe.¹¹⁻¹⁴ Patients who have been notified about incidental lung nodules have inadequate knowledge about what nodules are, the causes, the risk a nodule could be cancer, and the follow-up plan.¹¹⁻¹³ Clinicians' perspectives on optimizing patient-centered

care are not well understood, but communication has been identified as a modifying factor in screening for other types of cancer.¹⁵⁻¹⁹

This report is part of a larger mixed-methods study designed to evaluate the complex interactions and processes for patients with incidentally detected pulmonary nodules.^{20,21} In this report, we explored the experiences

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of primary care clinicians who care for patients with incidental nodules with a focus on their needs for system support, perceptions of patient distress, and communication strategies.

Materials and Methods

Overview and Setting

We conducted a qualitative study at two academically affiliated medical centers with outlying primary care clinics, VA Portland Health Care System (VAPORHCS) (Portland, Oregon) and Boston University Medical Center (BUMC) (Boston, Massachusetts), where some providers also saw patients in the Boston Veterans Affairs Healthcare System (Boston, Massachusetts). We enrolled primary care providers (PCPs) who care for patients with pulmonary nodules. We did not query how many patients with nodules they had encountered. For most patients with small, incidental pulmonary nodules, PCPs are responsible for notifying the patient and determining the follow-up plan in both systems. Neither system was routinely screening patients for lung cancer at the time the clinicians were interviewed.

The VAPORHCS uses an electronic flagging system to notify PCPs of a patient's first incidental nodule, which at the time of the interviews did not ensure adherence to follow-up imaging.² Similarly, at the time of interviews, BUMC did not consistently use a registry for nodule notification or monitoring follow-up adherence. At each site, PCPs received a letter inviting them to participate in one qualitative interview. All participants provided written informed consent as approved by the Institutional Review Boards at both sites (VAPORHCS #2630; BUMC #H-31643).

We used a patient-centered communication (PCC) theoretical model emphasizing five domains to guide our understanding of the commu-

nication strategies,²² but the flexibility of the interview guide allowed other themes to emerge. PCC domains include information exchange, patient as person (consideration of patients' feelings, preferences, and values), sharing power and responsibility (shared decision-making), therapeutic alliance, and clinician as person.²³ Using this framework, we evaluated how clinicians incorporate each domain into practice and what barriers or facilitators are involved in the communication process. Participants were interviewed by C. G. S. (pulmonologist), L. G. (psychiatrist), or both at the VAPORHCS and R. S. W. (pulmonologist) at the BUMC. The interview guide included queries about patient concerns, strategies to address distress, patient knowledge, follow-up strategies, and shared decision-making. Interviews were digitally recorded and transcribed. Each PCP is identified by a randomly assigned letter not related to his or her name.

We used ATLAS.ti 7.1.7 (ATLAS.ti GmbH) to organize the data and qualitative description²⁴ for analysis. Members of the study team (C. G. S. and L. G.) developed a codebook from five transcripts with themes derived from the interview guide and inductive study. C. G. S. and L. G. then independently coded the same transcripts. Collaboratively, the team refined the codebook and reviewed, coded, and discussed discrepancies in the coding for those original transcripts. C. G. S. and S. E. G. independently reviewed and coded the remaining transcripts, with L. G. separately reviewing and coding five to ensure consistency. Recruitment was terminated after 15 because of achievement of thematic saturation.²⁵

Results

We interviewed 12 VAPORHCS and three BUMC PCPs. Table 1 lists self-reported characteristics.

Information Exchange

Risk of Malignancy: PCPs believed most patients understood the nodule could be cancer, although most had not verified this assumption. Upon reflection, several PCPs seemed to question this supposition. For example, when asked if patients understood the risk, PCP H responded, "I assume that's what they are thinking." Most PCPs believed the risk of malignancy was usually

low for patients with small nodules but did not provide information regarding the personalized risk of malignancy directly to patients. Many PCPs reported inadequate knowledge themselves and were concerned about providing misinformation. Most did not use "risk calculators" to predict lung cancer risk but instead obtained follow-up imaging based on the radiologist's recommendations.

PCPs had varied approaches to discussing the risk the nodule was an early lung cancer (Table 2). Some PCPs did not use the word "cancer," whereas some reported they would only if the patient asked directly. Some also indicated variation depending on the patient's smoking and

TABLE 1] Cohort Characteristics

Characteristic	Statistic
Age, mean (SD), y	47 (10)
Female, No. (%)	10 (67)
Race/ethnicity, white, No. (%)	15 (100)
Provider type, No. (%)	
Internal medicine	9 (60)
Nurse practitioner	3 (20)
Family medicine	2 (13)
Resident	1 (7)
Time of practice, mean (SD), y	14 (10)
Time of practice at VA, mean (SD), y	7 (8)
Time of practice at current clinic, mean (SD), y	6 (6)

Percents are of nonmissing information. VA = Veterans Affairs.

health history. These PCPs expressed that talking about cancer increased distress and caused undue worry, as exemplified by PCP A: “It scares the poop out of people.”

Other PCPs believed it was important to use the word “cancer,” because the possibility of malignancy is important for the patient’s knowledge and is the reason that active surveillance is usually recommended. They also assumed that most patients realized the nodule was

related to cancer regardless. An additional reason was that it would encourage patients to return for surveillance imaging, especially in the case of current or former smokers. PCP J said, “I would at least let them know that [cancer] was a concern, just so that they understand that they need to get the repeat.”

Falling Through the Cracks

PCPs were very concerned that patients would “fall through the cracks” by not receiving recommended surveillance imaging. Most did not have a reliable method to ensure that follow-up occurs beyond ordering a CT scan for a future date and were frustrated by the lack of system solutions (Table 3). As PCP I said, “It’s a big pain. That’s the hardest part about this whole thing.” PCPs described several tracking methods: use of ancillary staff, calendar, or spreadsheet. These PCPs still reported they would most likely not know if a patient missed a scan until they came back for another office visit. When asked how they knew if a patient actually underwent follow-up imaging, PCP M said, “Great question. I don’t.” All believed the lack of tracking ability needed to be addressed by the health-care system.

A few PCPs indicated a small amount of worry was helpful to increase patients’ adherence to the follow-up

TABLE 2] Talk About Cancer

Talk About Cancer
<p>Don’t talk about cancer</p> <p>PCP A: We usually don’t mention lung cancer specifically; we leave it a bit more nebulous. “There’s a nonspecific abnormality. We don’t know what it means. But we do have some concern about it and we’re ordering further testing.” It [talk of cancer] scares the poop out of people...and once you give somebody that sort of fear, it needs to be addressed immediately. So to set that up, it’s a guaranteed confrontation to get this guy banging on the door saying “Why am I not getting in and getting this done right now?”</p> <p>PCP H: That would be very anxiety provoking to have that weighing on their mind all the way until it’s determined yes or no.</p> <p>PCP C: I don’t because I’m not that worried—yet. But I’m not specifically trying to avoid worrying the patient. I’m just giving them the information.</p>
<p>Do talk about cancer</p> <p>PCP M: I always tell them there’s a risk, or at least that they need to have it evaluated so that they <i>don’t</i> blow it off and not get the subsequent testing done. But at the same time I don’t give them numbers. Most of the time I find that they don’t hear them anyway, particularly on the phone.</p> <p>PCP B: ...I feel like you <i>must</i> bring that up because that’s something that if they’re not thinking it, then maybe I didn’t need to bring it up. But if they’re thinking it and I don’t bring it up then that’s what’s going to worry them when they go home. So I try to be very up-front with what we’re evaluating.</p> <p>PCP D: ...If I say cancer that’s all they are going to hear and they get scared. And that’s not the intent of the discussion in my mind, but I want to make sure I’m being honest with them so that they know why I’m ordering CT scans and expensive things with radiation in various intervals.</p> <p>PCP J: Just routinely I’d probably want them to know that I was concerned about cancer, but that we wouldn’t know anything until the next study was to be done.</p> <p>PCP I: And I generally do invoke the “cancer” word in the reason I’m getting the CT scan in the first place.</p>

PCP = primary care provider.

TABLE 3] Tracking Follow-up

Tracking Follow-up
No method to ensure follow-up happens
PCP A: I don't have a method for that. Let's say I get a report today, a CT scan with nonspecific nodules, recommended follow-up in 1 year. I put a note in the chart and I say "Radiologist reported some nonspecific nodules, recommended a follow-up CT scan in 1 year" and I order the CT scan right then and there for a year down the road. That's the only way I've got.
PCP C: I assume that if I put an order in for a CT scan and I put the date on it 6 months from now that someone in Radiology scheduling is going to contact the patient and schedule the exam.
PCP B: There really is no easy way to...make sure the patient gets the appropriate diagnostic workup in a timely manner.
How do they know if follow-up didn't happen
PCP A: I wouldn't have anything unless Radiology fed back to me that it didn't happen.
PCP N: Nobody calls me and tells me your patient did not get it, it's marked as a no-show in Radiology. So I won't know about it until the patient comes to see me in clinic.
PCP D: I would only know if I saw them back in clinic or for some reason was looking at their chart, and I could see in their imaging that they had this scan ordered and that it wasn't completed. But if they missed it I wouldn't get a reminder.
Methods to ensure follow-up
PCP H: Every patient that I see...I have the date that they came, who they are, when I'm supposed to see them back. And these little yes marks here [on the computer] are if there has been any consult submitted, requests for consultation with anybody, and actually if there are any imaging studies I put a "yes" in a different column.
PCP I: I put it on my problem list and almost everyone I see in my clinic I see at least every 6 mo. There are a few people who are on a 1-year follow-up, but if they have a nodule, I make sure that I am seeing them back when I actually think their next CT scan is due. I don't want a CT scan to fall through.
PCP O: I would put something in place for me to open the file, like a phone visit and you know, we're all computerized we don't have little paper tickler files any more so if I order a phone visit in 3 months, then there's going to be a reason for me to go back into that chart and I always look at the last note and, "OK there's our discussion about that, oh yeah, he needs a follow-up."
PCP J: I have a notebook where I write down what I've ordered in case it for some reason doesn't come back, so I check that.

See Table 2 legend for expansion of abbreviation.

plan. For instance, PCP G talked about the importance of a small amount of worry for ensuring the patient comes back in for follow-up imaging procedures, "And of course there is a subset of patients that don't care, [the nodule] doesn't worry them, and that I worry that they're not going to show up for the study."

Determining Follow-up: Almost universally, PCPs reported always selecting the follow-up interval based on the radiologist's recommendations. PCP C said, "I rely on the radiologist. I do whatever they say." Most PCPs assumed the radiologists were following guidelines and used the appearance of the nodule to make their recommendations. However, many did not know the source of follow-up guidelines, as articulated by PCP I, "I have no idea. I expect it is fairly arbitrary...I assume there are these radiologic standards."

Many PCPs reported using patient factors, mostly smoking history, to determine the date of follow-up when the radiology report gave a range of follow-up intervals.

Almost all chose the shorter interval if the patient had any risk factors for lung cancer. Many clinicians reported contacting a radiologist or pulmonologist to assist in determining appropriate follow-up if the recommendations were unclear or if they had other concerns.

Patient as Person

Most PCPs reported that patients rarely asked questions or wanted more information after notification. When probed whether they asked specific questions about the patients' level of distress or worry, PCP A exemplified what many reported, "Not usually...because I usually preface [the conversation] to address that before we get to that level [of distress]." Some PCPs actively tried to mitigate patients' distress by providing information in a patient-friendly way, avoiding jargon, not using terms like "cancer," or "nodule," or by using language to minimize the severity of the finding.

Many PCPs relied on their patients' nonverbal cues to determine distress. PCP A described how seeing a

patient face-to-face was informative, “If you’re with the person, you hear it in the tone of what they’re saying or in the body language.” Many PCPs reported that most of patients’ distress related to a desire for further, immediate testing (such as obtaining a biopsy) rather than continuing with surveillance imaging. In those instances, PCPs said they would provide more information, provide a phone number for further questions, and explain the reasoning behind their recommendation. “If [the patient] wanted a biopsy, if the case wasn’t strong, I would say that it carries risks of bleeding, and infection, and pneumothorax. And I would try to dissuade her and if [the patient] wouldn’t leave my office without further intervention, I would say, ‘OK. Let me have you speak to one of the specialists in pulmonary,’” said PCP F.

Many PCPs reported that the length and quality of their relationship with the patients was associated with insight into the patients’ reaction after notification, which simplified how to tell the patient (ie, what medium of notification, what level of detail, etc). PCP M said, “You pretty much know your nervous Nellies. And you know who’s going to worry and you know whose wife is going to worry.” Since they knew the patient best, several PCPs expressed having direct responsibility for informing the patient about the nodule.

Shared Decision-making

When asked about decision-making and patient preferences regarding management options, most PCPs did not actively involve the patient in the decision. Most of the time, the PCP made the decision and the patient agreed. PCP K said, “I basically just tell [the patient].

I don’t really say why I came to that decision or how I came to that decision.” However, in the rare occurrence that the patient expressed unease over the plan for surveillance imaging, PCPs usually agreed to change the timing of follow-up imaging or consult a pulmonary clinician. A handful of clinicians said that it depends on the case (nodule and patient characteristics) if they discuss follow-up options with the patient (Table 4).

Discussion

This study explores the experiences of PCPs caring for patients with incidentally detected pulmonary nodules. We found PCPs lack information to effectively communicate about nodules and need system support to assure recommended imaging. PCPs believed most patients did not have substantial distress as a result of nodule detection and used several strategies to reduce or prevent negative outcomes. Most PCPs did not include patients in the decision-making process.

One of the key domains of PCC is adequate information exchange between clinician and patient.²⁶ Patients often receive inadequate information about their nodule and want more information about risk and about nodules in general.^{8,11,13} Without adequate information, they substantially overestimate their risk of cancer. PCPs interviewed based their opinions on subjective notions about what information or communication strategies they assumed patients preferred. Clinicians want to give patients information but need to know what patients desire. PCC strategies are also hindered by PCPs’ lack of knowledge about nodules. Systems-based solutions, such as providing risks of lung cancer in radiology

TABLE 4] Shared Decision-making

Shared Decision-making
Willingness for shared decision-making
PCP M: If the patient is just really nervous about it...I'll usually try to compromise with them and I'll try to put them at ease and say, "you know, there's really no reason to do anything further." Some of them, you know, [say] "let's cut it out right now." And I try to explain that that risk is much greater than following it. And a lot of times I will compromise and we'll get the CT scan earlier just to put them at rest. But not enough earlier to really make too much of a difference.
PCP B: The back and forth really would be in not clear-cut cases.
Lack of shared decision-making
PCP L: I'd say I pretty much tell them what their radiologist recommends. I guess my patient population tends to be one that says, "You're the doctor." They're not a population that questions things a lot...They tend to be pretty adherent to recommendations. I can't say there is a shared decision process going on. It's kind of like the radiologist is deciding; I'm respecting the radiologist; they're respecting the radiologist.
PCP G: I can't think of a recent incident where a patient wanted sooner follow-up than I was recommending. I think should that situation arise, if I really believed that follow-up wasn't necessary...I feel pretty confident in being able to explain to the patient why it wasn't necessary.
PCP C: I just order it. Put the order in.

See Table 2 legend for expansion of abbreviation.

reports, may address this gap.^{27,28} By combining the results of our previous studies, we provide suggestions for methods to improve communication (Table 5).

Patients rely on the health-care system to coordinate follow-up imaging, but PCPs expressed concerns about patients falling through the cracks.^{11,13} Health-care systems should consider developing tracking tools to monitor and ensure adherence.²⁹⁻³¹ Such tracking systems have been recommended as a critical component of high-quality screening programs,³² along with establishment of registries.⁹ Development of both should include methods to improve patient-centered care. In addition to tracking systems, high-quality patient-clinician communication may improve patient adherence to follow-up recommendations.³³⁻³⁵

PCPs seem to underestimate the frequency and magnitude of patients' distress.^{8,11-13} Clinicians may need to develop strategies to more directly query patients about distress, since reliance on nonverbal cues and commu-

nication via letter or phone may be insufficient. PCPs use information as a means to reduce distress, but patient satisfaction with information exchange and more accurate knowledge of self-perceived lung cancer risk are not associated with distress.¹⁴ Thus, high quality communication strategies that include attention to the patient as person domain and shared decision-making may be necessary to address these concerns.^{23,36}

Many patients with nodules and other medical conditions want to share decisions with their clinicians.^{11,12,37,38} However, both PCPs and pulmonologists report seldom engaging in shared decision-making.³⁹ Clinicians may not feel like they have an option either. Guidelines for follow-up are sometimes unclear and seem to indicate that all patients with small nodules should continue surveillance. Although this is accurate in some portion of patients, there is another portion for whom other decisions may be reasonable, such as no workup at all.⁴⁰ The use of decision aids leads to appropriately conservative

TABLE 5] PCP and Patient Perspectives on Communication and Possible Solutions

PCP Beliefs and Actions	Patient Desires and Knowledge	Possible Solutions
Do not discuss risk of malignancy	Do not receive adequate information about the risk of cancer, the causes of nodules, rationale for active surveillance, and follow-up plan details	Report the semiquantitative risk of lung cancer
Do not use the word "cancer" to prevent distress	All realize the nodule is associated with lung cancer	Provide information about the causes of nodules, rationale for active surveillance, and follow-up plan details
Nodule is a minor diagnosis in comparison with other health issues so not often discussed	Although nodule may not be a priority, information still desired to acknowledge patient uncertainty about diagnosis	System-level methods to improve patient knowledge
Often notify patients by letter or phone	Value in-person communication	If no other system exists to improve knowledge and mitigate distress, PCPs should discuss the patient's concerns in person
Think patients can easily contact PCP for questions or clarification	Clinicians are difficult to contact within existing systems	Health-care systems should develop tools to ensure ease of communication
No systemic method to monitor adherence to follow-up recommendations	Rely on PCP or health-care system to ensure follow-up	Health-care systems should develop tools to monitor and ensure adherence
Believe distress is uncommon	Distress is common and should be addressed	Communication strategies should include methods to address patient as person and shared decision-making considerations
Believe distress is mitigated by current information exchange communication	Improved patient knowledge may not decrease distress	Actively elicit patient feelings
Do not involve patient in decision-making	Want to understand and participate in the rationale and decisions regarding the follow-up plan	Improve patient knowledge of follow-up decisions, including benefits and harms of each; use decision aids

The views expressed are generalizations and may not apply to all PCPs or patients. See Table 2 legend for expansion of abbreviation.

strategies in other settings³³ and should be studied for their influence on decision satisfaction and other outcomes. The use of nurse navigators, counselors, or risk/benefit assessments may also be helpful.^{29,41}

There are limitations to our study. The results may not be generalizable to other settings, such as screening programs, other health systems, or different clinician specialties. The authors are not aware of any landmark study that examines the prevalence of these types of resources. Because our sampling was purposive, we believed it important to include a trainee, although they may not have been as familiar with nodules. We did not directly observe communication, so results may not reflect actual practices; however, as widely recommended, we are coordinating results with our qualitative and quantitative studies among patients with nodules to develop a more complete assessment of patient-clinician communication.²¹ Our results are subject to moderator acceptance bias, wherein participants may respond with what they think the interviewer wants to hear.⁴² Finally, our results offer insights into potential communication strategies (Table 5), but tools and interventions should be tested prior to widespread dissemination.

Conclusions

We found that PCPs attempt to provide quality patient-centered care. However, it did not appear that PCPs were fully meeting the needs that patients expressed.¹¹⁻¹³ PCPs and patients are concerned about falling through the cracks, but there are no systemic methods to improve adherence to active surveillance strategies. Patients often believe that having a pulmonary nodule is only one problem¹¹ of many, so solutions that simply expect PCPs to spend more time to individually address these concerns at the expense of other problems are unlikely to be associated with overall improved care. Instead, health-care systems, with the support of pulmonologists, should develop comprehensive strategies that improve PCPs' and patients' knowledge about pulmonary nodules, better identify patients who experience distress and incorporate strategies to mitigate that distress, and enable tracking of follow-up imaging. Pulmonologists can also assist primary care colleagues by providing accurate information to counsel patients and assisting in managing conversations about the risk of cancer. If these systems are not developed, lung cancer screening is likely to exacerbate these problems.

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