


Patient Experience of Managing Adherence to Repeat Lung Cancer Screening

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Abstract

Lung cancer screening (LCS) is a process involving multiple low-dose computed tomography (LDCT) scans over multiple years. While adherence to recommended follow-up is critical in reducing lung cancer mortality, little is known about factors influencing adherence following the initial LDCT scan. The purpose of this study was to examine patients' and providers' depictions of continued screening and their understandings of patients' decisions to return for follow-up. Qualitative methodology involves interviews with patients about their understanding of the screening process and perceptions of lung cancer risk, including motivations to adhere to follow-up screening and surveillance. Analysis of interview transcripts followed the general procedures of grounded theory methodology. Patient adherence to LCS was influenced by their understanding of the process of screening, and their expectations for the next steps. Perceptions of lung cancer risk and associated motivation were not static and changed throughout the screening process. Recognizing that patients' motivations may be dynamic over the course of screening and surveillance will assist providers in helping patients make decisions regarding continued engagement with LCS.

Keywords

cancer, patient expectations, patient perspectives/narratives, qualitative methods

Introduction

The United States Preventive Services Task Force (USPSTF) recommends annual lung cancer screening (LCS) with low-dose computed tomography (LDCT) in adults aged 55 to 80 with a substantial history of smoking (1), but less than 15% of eligible individuals nationally initiate LCS (2, 3). Of those who do, adherence to recommended follow-up or repeat screening is variable, ranging from 35% to 86% (4–8), and adherence decreases with subsequent rounds of screening. To achieve the goal of reducing lung cancer mortality, patients must continue to adhere to annual LCS and interim surveillance over many years. Some research has focused on describing and improving the initiation of screening (9–15), but there is limited research into adherence to follow-up testing (16). It remains unclear how patients make decisions about their continued engagement with screening and surveillance, the factors that influence these decisions, or the sources of information patients use.

Per the widely accepted Lung CT Screening Reporting & Data System (LUNG-RADS) guidelines issued by the American College of Radiology (17), the frequency of recommended LDCT scans is driven by the risk of lung cancer, inferred from LCS findings (ie, size and appearance of any screen-

detected nodules). Initial LCS will be either negative (no nodule or very small nodule) or a larger nodule (or other abnormality) that calls for further evaluation. Small or stable nodules suggest a benign finding and the continuation of annual screening, whereas indeterminate or suspicious nodules warrant interim LDCT surveillance or more invasive testing.

While previous research suggests that risk perception does not change at 1 year after LCS (18, 19), little is known about how patients' perceptions of risk influence the decisions they make about continued engagement with screening and surveillance. Theoretical models of adherence to preventive

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health measures, such as the Health Belief Model (HBM), identify 6 factors that play a role in influencing patient intention and decision making in initiating health screening (20–23). The HBM identifies how perceptions of *susceptibility or vulnerability*, and *severity* influence health-related behavior. Modifying factors, including *personal characteristics*, *perceived threat*, and *cues to action*, may combine with perceived and real *benefits and barriers* to explain how patients make decisions about initiating preventive care such as LCS. The extent to which these factors apply to patients' intention to adhere to screening follow-up and surveillance in LCS is not properly understood.

Adapting the HBM to account for adherence to continued screening draws attention to successive LCS findings and potentially changing perceptions of risk that may reinforce initial decisions or precipitate changes—that is, patients may be motivated to remain engaged or decide to suspend participation. Yet, patients' perceptions of risks and their communication with providers remain poorly characterized. Moreover, while many LCS programs have implemented processes designed to ensure LCS adherence, little is known about their influence on patient decisions. Intention to adhere to follow-up has been studied in colorectal (CRC) and breast cancer screenings (24–27). While the intention to adhere was high, there is no consistency in the roles played by perceived susceptibility and severity (28). Understanding how these perceptions might change throughout the screening process, in relation to incoming information from serial screening exams, is important in determining how best to maintain adherence.

In this article, we draw upon interviews with patients who have initiated LCS in order to describe how risk perceptions, and patient motivation/intention to adhere to LCS was influenced by patient understanding of the screening and surveillance process, and modified perceptions of susceptibility given the results of previous CT scans. Qualitative research is essential in contextualizing elements of the HBM, leading to an appreciation for how patients make decisions about screening (29).

Table 1. Screening Results and Participant Adherence.

	Negative finding Continue annual screening	Indeterminate finding Close surveillance	Total
Returned as scheduled	12	9	21
Late for follow-up	1	3	4
Did not return for follow-up	5	2	7
Declined follow-up LDCT	2	0	2
Total	20	14	34

Abbreviation: LDCT, low-dose computed tomography.

Methods

The study involved in-depth qualitative interviews with 34 patients from LCS programs at 3 Veterans Administration (VA) medical centers. Interviews were conducted via telephone by a PhD-trained qualitative researcher (CG) and lasted, on average, 35 min. Interviews were analyzed between 2015 and 2018. To be included, a patient must have received at least 1 screening chest LDCT with the recommendation to return for follow-up screening or surveillance. We sought diversity in patient experiences of LCS and asked Screening Coordinators at each site to identify 3 groups from the registry of screened patients: (1) those who returned, as recommended, for additional annual screening or surveillance; (2) those whose return for recommended follow-up was delayed; (3) patients who did not return for recommended follow-up. Recruitment letters were mailed to 105 eligible patients. Seven patients indicated an unwillingness to participate by returning an opt-out card. Phone calls to the remaining participants (n = 98) resulted in the enrollment of 34 patients: 21 who were adherent, 13 who were non-adherent (delayed or no follow-up) (Table 1). All participants were male, between the ages of 54 to 74, with a mix of negative LCS results (with recommended continued annual screening) and indeterminate nodules (with recommended interim surveillance).

Semi-structured, in-depth interviews with participants addressed their experiences with initiating LCS, including the process of completing the initial LDCT scan and experiences with any subsequent LDCT scans. Patients were invited to relate their reactions to the results of LDCT scans and the meaning of these results in the context of their risk for lung cancer as well as their overall health. Interviews explored reasons for prompt adherence and delays in follow-up scans or patient perceptions for difficulties in making and keeping appointments, including their experiences with scheduling appointments. They were asked to recount any difficulties they had with the screening process and how these may have influenced their decision to present for follow-up LDCT scans. Attention was given to the significance of their perceived risk for lung cancer and their intentions to continue to participate in LCS and surveillance.

Interviews were recorded and transcribed verbatim in order to facilitate data analysis using Atlas.ti(30). Analysis followed the general procedures of grounded theory methodology, strongly informed by the “sensitizing concepts” provided by a modified HBM, including perceptions of susceptibility and severity, perceived threat of lung cancer, barriers and benefits of LCS, and cues to action. Additional codes were derived iteratively through inspection of the data. All authors marked an initial set of transcripts by codewords to identify passages indicating conceptually distinct attributes relevant to the model(31, 32). Discrepancies in coding were resolved through discussion until consensus was reached and a codebook was established. Subsequent coding was performed by CG, with regular feedback from the study team. Through successive rounds of

coding and memo-writing, distinct themes of perceptions of LCS and barriers and motivations to adherence were identified. These themes were scrutinized by a team of 3 researchers with significant qualitative analysis expertise for consistency through comparison to possible counterexamples(33, 34). This study was approved by the Institutional Review Board, and written informed consent was obtained from each participant.

Results

Major themes that emerged from data analysis included the patient's general motivation to adhere to LCS, their understanding of the LCS process and expectations for the next steps, and resulting modifications to their perceptions of risk and motivation for adherence. Additionally, we present how the results of previous LCS exams influenced perceptions of risk and adherence decisions.

General Motivation to Adhere

Patients were generally receptive to LCS and were motivated to persist with continued screening and surveillance. Statements portraying motivation to return for follow-up reflected concern about underlying risk, willingness to follow clinical guidance, and belief in the value of health screening. This reasoning was common regardless of actual adherence behavior.

“With my family history, my father dying of lung cancer, they wanted to have it done and I had no objections, whatsoever, to it.” (*returned for screening after delay*)

“If my doctor wants me to have another one next year, then I probably would do it.” (*returned as scheduled*)

Understanding of the LCS Process and Expectations for Next Steps

While participants were motivated to follow clinician recommendations, perhaps the most influential driver of patient adherence was the extent to which they understood the screening process. Participants frequently did not recall or misunderstood the education they may have received about the need for repeated annual screening, or additional follow-up of screen-detected lung nodules. They were also often unaware of the intensity or duration of the process, which sometimes led to unintentional nonadherence.

“They didn't discuss a next step.” (*did not return*)

“Everything came back negative, so there was no more discussion about it.” (*returned after delay*)

However, others did return as scheduled, despite a poor initial understanding of screening and what it would entail:

“When I did my last screening, they sent me a letter that I did not understand what they were talking about.” (*returned as scheduled*)

Multiple participants expected that, unless there was a suspicious finding, they would not receive communication from their providers. So, when they did not receive the results in an expected time frame, either by phone or via mail, they presumed their results were not concerning and that there was no additional action needed.

“Well, if I don't hear anything from them, I know everything's okay.” (*returned as scheduled*)

While the participants were contacted and scheduled for a follow-up LDCT scan, lack of understanding of the screening process holds potential for delays in adherence.

Modified Risk Perceptions and Adherence Motivation

Perceptions of lung cancer risk and associated motivation to adhere were not static and could change over the screening process. One of the elements that patients referenced as contributing to their motivation to adhere was LCS results. However, the effects of LCS results on adherence were not consistent in a single direction. Sometimes, the information led patients to either delay or decline recommended tests, while in other cases it increased motivation to adhere.

After a Negative Finding

A negative finding could be cited as a reason to forego additional testing, or as motivation for returning. Some patients were less motivated to return after a normal scan.

“I had no intention of going back for another scan. I didn't see the importance of it, since it was normal the first time...but I said ‘I'll go have it. Doesn't make any difference. It's not like it's a big deal.’” (*returned as scheduled*)

However, negative findings could also motivate participants to remain engaged in screening, often related to underlying concerns about cancer:

“You figured after sixty years [of smoking], something *had* to be in there... I want to go back in.” (*pt. returned after delay*)

“Each time I went in, I felt more confident that things were gonna be normal.” (*pt. returned as scheduled for annual screening*)

In the first case, the patient was surprised by negative results, and intended to return to confirm there was no cancer. In the second case, annual screening provided increasing reassurance. In both cases, the participant expressed initial

concern about potential results. That concern was modified as a result of the findings from the screening CT.

After an Indeterminate Finding

Finding an indeterminate nodule led patients to revise their risk perceptions and intentions to adhere. For some, the idea of monitoring a small nodule to ensure it was not cancer was reassuring and motivated them to return as recommended:

“So they did it again and it actually had gotten smaller, so they said they’ll do it again in a year...[Now I care] probably a little bit more than I did...more willing to go through their program.” (*pt. returned as scheduled*)

Others interpreted the recommended surveillance interval as indicative of the seriousness of the finding, decreasing motivation to adhere:

“Well, I just assume that if they were worried about it they would’ve scheduled an appointment earlier. So, in fact, it makes me think, maybe I’m okay.” (*pt. returned after delay*)

Participants cited prior LCS results as information they used in making decisions about returning for follow-up. The reasoning they describe indicates that perceptions of risk changed over the course of screening and surveillance, and that an important driver of these changes was prior LDCT results. These changes in motivation reflect a dynamic process of risk evaluation.

Discussion and Conclusion

Patients who initiate LCS come with a mix of expectations that they use to explain their intended persistence with screening and surveillance. These expectations sometimes change over the course of screening. While most patients who initiate LCS intend to follow recommendations for follow-up, their understanding of what is expected varies. Through interviews with patients who had initiated LCS in VA, we identified 3 important elements that influenced patient decision making regarding repeat cancer screening: intention to adhere to clinical recommendations; understanding of the LCS process; and dynamic risk perception informed by LCS results. These findings have important implications for LCS programs and underscore the continued need for providers to educate patients about the LCS process and the importance of adherence to recommended follow-up.

Given the need to obtain multiple chest CTs over many years and at varying intervals, depending upon findings, we anticipated that adherence would be problematic for many participants (35, 36). However, we found that patients were generally motivated to return for follow-up and intended to follow the recommendations of their providers. When LCS was first introduced, providers did not consistently educate

patients on the process of screening and surveillance, notably the need to return for multiple LDCT scans over a number of years, at sometimes varying intervals. Patients’ resulting poor understanding of the expected next step could lead to inadvertent nonadherence.

LCS programs can leverage the underlying motivation of patients to adhere to the LCS process to re-engage patients who have misunderstandings about the next steps in recommended testing. Prior studies suggest that LCS tracking and navigation systems overseen by an LCS coordinator can be effective in achieving high rates of adherence(7, 8).

Our study supports the importance of providers providing basic information about the LCS process before initiating screening (as required by Medicare(37)) and then explaining expectations for the next steps (annual screening or additional testing for a screen-detected finding) in more detail at the time of disclosure of LCS results. Patient education has been identified as a necessary component of an LCS program (38, 39). Clinicians should clearly communicate expectations about adherence to patients, including the duration and possible intervals of CT scans, and what they can expect in the form of communication from clinicians. Kindratt, et al found that involving patients in screening decisions led to greater uptake of cancer screening(40). Clinicians can seize on the potential influence of prior CT screening exam results to have conversations with patients about their perceptions of risk and motivations to continue to adhere to screening and surveillance recommendations. The more patients understand this process, the better they should be able to participate in the care of their lungs and the management of their lung cancer risk. Indeed, we found that patients cited their providers’ recommendation as a compelling reason to adhere even when the patient’s own motivation to continue with the LCS process was low.

Recommendations for LCS programs to date have emphasized the role of systems to track LCS findings and ensure adherence to recommended testing(38, 41), but little attention has been paid to patient use of LCS results in making decisions about adherence, and their impact on motivation to adhere. Evaluating risk is a dynamic process that is modified throughout LCS. An important element in patient decision making about adherence is their initial perception of risk and expectations about the screening process. Sinicrope et al found that a perception that LCS screening was highly accurate correlated with higher perceived risk(42). These previous expectations shape the interpretation of screening results and decisions about continued adherence(43, 44). In some cases, results led participants to continue with screening or surveillance, while others decreased motivation to adhere. Similarly, in other cancer screening settings, the roles played by perceived susceptibility and severity on intention to adhere to screening are inconsistent(28). Regardless of how patient risk perceptions were modified, an important finding of this study is that risk perceptions are not static, and thus, neither is motivation to remain engaged in screening. Prior work in both the LCS and

incidental pulmonary nodule setting confirms that patient concern, an indicator of risk perception, evolves over time. Slatore et al found that distress is common among patients with screening-detected nodules, but that this distress does diminish over time(45–47). Clinicians should recognize this dynamic process, and continually re-evaluate risk perceptions, associated concerns, and motivation to adhere in order to assist patients as they make decisions regarding engagement with LCS. The benefits of this approach are clear, at least in the setting of incidental pulmonary nodules, where high quality patient-centered communication has been shown to mitigate distress and increase adherence to recommended evaluation(47, 48).

This study has limitations. While it would have been informative to compare risk perceptions and motivations between those who were classified as adherent and those who were non-adherent, and to inspect differences between the screening and surveillance groups, the small numbers within each non-adherent category did not allow for definitive conclusions. Related to this, we relied upon self-reports of adherence and LCS results as we were unable to access participants' charts to verify this information. However, regardless of the accuracy of patient knowledge of these, we do capture how their perceptions motivated their behavior. Also, recruitment of participants may have excluded those who were intentionally non-adherent—that is, those who refused to return may have also been less inclined to participate in the study. While the number of female veterans is increasing, the generation that is currently eligible for LCS is still predominantly male. Therefore, the data, and analysis, is limited by not including a female perspective.

A significant finding of this research is that patients' risk perceptions are not static. Rather, evaluating risk is a dynamic process that is modified throughout the process of LCS. In this case, patients used the results of prior screening tests in making decisions about returning for follow-up scans. Our findings inform strategies LCS programs can employ to improve adherence to LCS, including shared decision making(49) and the importance of revisiting these decisions perceptions of risk change. These findings can also inform strategies to improve adherence to other cancer screening programs that involve multiple screening and/or surveillance exams over multiple years and with varying intervals (eg breast, cervical, and CRC screening).

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Statement of Human Rights

All procedures in this study were conducted in accordance with the VA Bedford Healthcare System IRB's approved protocols.

Statement of Informed Consent

Written consent was obtained from the participants for their anonymized information to be published in this article.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Approval

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