



Short communication

Lost to follow up?: A qualitative study of why some patients do not pursue lung cancer screening

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ABSTRACT

Although national guidelines recommend lung cancer screening for adults at high risk, only a small proportion of eligible adults in the US have been screened. The goal of this study was to understand barriers to screening among a specific but important population: patients who have been referred for screening, but who have not completed the test. We used semi-structured interviews to explore barriers to screening among patients at two academic, safety-net primary care practices. We included patients who had been referred for screening at least 6 months prior but who had not completed the test. Among interviewees (N = 16) a consistent theme was a lack of knowledge about the purpose and process of screening. Despite being referred for lung cancer screening, participants expressed that they knew little about how screening was performed or what it was intended to achieve. Preferences and values also played a role in why some participants did not return for screening. Our findings suggest that lack of knowledge about screening is an important barrier to use, as patients are unlikely to prioritize a test if they know little about it.

1. Introduction

Lung cancer screening with low-dose computed tomography (LDCT) has been shown to reduce lung cancer mortality among high risk adults. (The NLST Research Team, 2011; de Koning et al., 2020) In 2013, guidelines from the US Preventive Services Task Force (USPSTF) recommended screening for adults ages 55–80 who were current tobacco users or who had quit in the last 15 years, and who had at least a 30 pack-year tobacco use history. (USPSTF, 2021) Medicare began covering LDCT for adults 55–77 who met these tobacco use criteria 2015. (CMS, 2015) However, despite guideline recommendations and insurance coverage, adoption of LDCT has been slow, with only about 18 % of eligible patients screened nationally by 2018. (Kee et al., 2018) Updated guidelines from the USPSTF issued in 2021 substantially broadened the eligibility criteria, and it is estimated that nearly twice as many adults in the US are now eligible for screening (Landy et al., 2021).

Understanding barriers to screening will be critical for effective implementation in this broader population. A number of studies have identified key barriers to screening including lack of access to organized screening programs, the difficulty and complexity of identifying eligible patients, and negative perceptions of screening among providers and

patients. (Wang et al., 2019; Triplett et al., 2018; Carter-Harris and Gould, 2017; Kale et al., 2019) However, even when screening programs are available and accessible, more than a third of patients referred may not be screened. (Leishman et al., 2021) The goal of this study was to understand what barriers to screening might remain, even after patients have been identified as eligible and have been referred to a comprehensive screening program. (American Thoracic Society and American Lung Association, 2018) Specifically, we used qualitative methods to understand perspectives of patients who had been referred for LDCT by their primary care provider, but who had not completed the test. Understanding the views and experiences of this group is critical for identifying important barriers to use of lung cancer screening, even when screening is nominally available.

2. Methods

We conducted in-depth, semi-structured interviews with patients who had been referred for LDCT based on 2013 USPST guidelines at least six months prior to recruitment, but who had not yet scheduled the imaging test. Participants were eligible if they spoke English and could participate in an audio interview. Participants were initially approached

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about participation by their primary care provider (PCP), then contacted by phone or in person after a clinic visit by study staff if they expressed interest in participation. Participants were offered \$25 compensation for their time. All participants were identified as eligible prior to March 2020. We used criterion sampling to select participants, screening consecutive patients who were scheduled to be seen in primary care clinics on days when study staff were available for recruitment. (Kuzel, 1999).

We recruited participants from two academically affiliated safety-net primary care practices. These clinics use a centralized shared decision-making model. In this model, PCPs order LDCT for patients who are eligible for and interested in screening. When patients call to schedule the LDCT, they are simultaneously scheduled for a structured shared decision-making visit with a nurse practitioner, which occurs prior to the LDCT. After the shared decision making visit, patients may elect to continue with the LDCT or not. (Mazzone et al., 2017) Thus, patients included in this sample had discussed screening with their primary care providers and had been referred to the screening program, but had not yet undergone a formal shared decision-making visit.

We used semi-structured interviews to identify perceived barriers to screening. Interviews used a standardized guide that included open ended questions to elicit participants' perspectives on lung cancer screening and reasons why they had not been screened. For patients who indicated they knew or remembered little about lung cancer screening, the interviewer could offer some basic information about the goals of lung cancer screening and how it is performed as a prompt. Interviews were conducted by phone, recorded, transcribed verbatim, then inductively coded by two independent reviewers (IR and TP). Reviewers grouped codes into categories using a constant comparative approach, with discrepancies resolved through discussion. Reviewers then collaboratively developed themes from categories. (Corbin and Strauss, 2014) Analyses were conducted in Microsoft Word and Excel. Recruitment was stopped after interviews yielded repeated themes. We conducted interviews between September 2019 and June 2020. Data were analyzed between July and September 2020. This study was approved by the Yale Human Investigation Committee and all participants provided informed consent.

3. Results

We identified 25 eligible patients of whom 16 were enrolled and included in our final sample. Nine patients met eligibility criteria but either declined participation or could not be reached for interview. The mean age among participants was 65 years, 50 % were female, 44 % were White and 56 % were Black. LDCT exams among participants in this sample had been ordered between October 2016 and October 2019.

A common theme in interviews was a lack of familiarity with the purpose and process of lung cancer screening. Many participants indicated they knew little or nothing about lung cancer screening, despite the fact that LDCT had been ordered by their primary care provider. Others had inaccurate understandings of the test, conflating LDCT with plain films, pulmonary function tests, diagnostic testing, or smoking cessation programs. Importantly, some participants indicated that inadequate knowledge of lung cancer was a barrier to screening, noting that because they were unfamiliar with screening, it was simply not a priority, or it was not something they understood clearly enough to pursue. For example, one patient noted, "Just not knowing [about lung cancer screening]...I just never, you know, thought about it or cared about it." Another said, "As soon as I can find out what to do, I can, I can take some kind of action, but it's just very vague what they've said to me so far," (Table 1).

Participants also identified several other barriers to screening beyond inadequate knowledge (Table 1). Some participants had competing demands that took priority over screening. For example, one participant said, "My main focus has been my back, 'cause I have symptoms from my head to my feet and that is what was...my issue."

Table 1
Interview Themes.

Theme	Illustrative Quote(s)
<i>Knowledge of Lung Cancer Screening</i>	
Lack of basic familiarity with lung cancer screening.	"I don't know. I don't - like I said, I don't even know. What, what does the test consist of? What do I have to do?"
	"I heard about it, but I really don't know much about it, you know, about the screening or anything."
	"I really don't know anything about it."
	"I never heard of it, but I, I know they...they're around."
Inadequate knowledge as a barrier.	"Just not knowing [about lung cancer screening] ...I just never, you know, thought about it or cared about it."
	"As soon as I can find out what to do, I can take some kind of action, but it's just very vague what they've said to me so far."
<i>Other Barriers to Lung Cancer Screening</i>	
Patients have competing priorities.	"My main focus has been my back 'cause I have symptoms from my head to my feet and that is what was...my issue."
	"I have spinal problems and leg problems and I really haven't been driving much so I'm kind of relying on getting rides...with everybody busy with working and things like that and it's, you know, all my other appointments, it's just, uh, it just hasn't worked out so far."
Screening contributes to the burden of medical care.	"I have too many appointments and that's kind of hard on me, trying to get all my appointments to go to."
Concern about what the test might show.	"It was just me being a knucklehead. Saying I'd go and I wouldn't go. And I had to go to [in for the test]...but then I cancelled. 'Cause I didn't want no bad news."
Concern about discomfort during the test.	"I'm a Vietnam vet and I got PTSD, so I cannot be enclosed in the machine."
Confusion about scheduling process.	"I believe I have a date coming up, or they're planning to have a date, or I have to call some [one] or something."
<i>Positive Views of Screening</i>	
Early detection is beneficial.	I'm under the impression that it'd be something beneficial in case, you know, anything shows up. The earlier you detect something, it'd be easier to treat.
Self-knowledge is valuable.	It's always good to know if there is something there...or [if] something's not right, I would like to know. You know, versus not knowing...it's just...kind of crazy not to know.
Physician's advice is trustworthy.	My primary care doctor,... she stressed for me to do it, you know? She was, she was a good doctor, a very good doctor. She cared about her patients.

Another noted that screening adds to the burden of medical care or worried that the test itself might be uncomfortable. Some were hesitant to be screened because of the possibility that the test might bring unwelcome information. Lastly, some participants were confused about logistics including the scheduling process.

When provided with basic information about lung cancer screening in the interview, some participants expressed positive views. Specifically, participants noted that finding cancer early may be beneficial, and for some, knowing whether they had lung cancer was better than not knowing. Some participants also noted that trust in their physician's advice was a reason to proceed (Table). For example, one participant said, "My primary care doctor,... she stressed for me to do it, you know? She was, she was a good doctor, a very good doctor. She cared about her patients."

4. Discussion

We explored barriers to lung cancer screening in a specific but important group: patients who were referred to a lung cancer screening program but who never pursued screening. Consistent with previous studies, we found that patient preferences and values play a role in how patients approach lung cancer screening. (Wang et al., 2019; Carter-Harris et al., 2017) However, a critical theme in our interviews was a lack of knowledge about screening. Participants were unfamiliar with aspects of the test, including how it is performed and what the purpose is. This uncertainty likely played a key role in adherence - participants were unlikely to complete a test they did not understand.

Importantly, patients in this study had not undergone a formal shared decision-making discussion which, at our institution and others, is centralized and performed during a dedicated visit. Centralizing shared decision-making has been proposed as an efficient approach, alleviating time pressures on primary care providers. Centralizing the process also ensures that the shared decision making visit is conducted by a clinician with expertise and experience. (Hoffman et al., 2021) Given these advantages, many centers have adopted this model. (Alishahi Tabriz et al., 2021) However, our results suggest that despite the advantages of this model, it also may leave gaps in patient understanding and opportunities for attrition. If patients do not receive adequate information about lung cancer screening at the point of care, they may be less likely to ever attend a formal shared decision-making visit.

Our study also complements a broader literature suggesting that gaps in knowledge contribute to underuse of lung cancer screening across a variety of settings and along the continuum of care. A study of patients who declined screening after a shared decision-making discussion with their primary care provider suggested that inadequate understanding of screening also contributed to some decisions to forgo screening. (Carter-Harris et al., 2017) More broadly, several studies have demonstrated that patients eligible for lung cancer screening often have little knowledge of it and that patients with greater knowledge of screening are more likely to pursue it. (Carter-Harris et al., 2017; Monu et al., 2020) Placed in this context, our study underscores that lung cancer screening is simply unfamiliar to many patients, and patients may need information and education at multiple points along the continuum of care to make informed decisions.

Our work highlights that lack of knowledge is not the only reason some patients elect not to be screened. Participants also cited a variety of reasons they had decided not to pursue screening that largely reflected their preferences and beliefs. Given the tradeoffs of lung cancer screening, the goal of implementation is not to necessarily screen everyone who is eligible. Rather, patients should have the opportunity to learn about lung cancer screening and to make a decision that is in line with their own values. (Hoffman et al., 2021) Opting out of screening is an acceptable and even welcome outcome if it is a choice that reflects a patient's preferences and values. However, crucial to any such decision is patient education and understanding. Patients must be adequately informed about lung cancer screening, so that they can fully consider their preferences in the context of the potential benefits and risks of screening.

Our study has some important limitations. In particular, our single-center design with a focus on patients seen in a safety net practice may limit generalizability. We also interviewed a small sample, and though we observed many consistent themes among participants, it is possible that a larger sample could have revealed additional themes.

5. Conclusions

Lung cancer screening is now recommended for a substantially larger group of adults, and implementation of screening will be a central challenge. Our findings identify lack of knowledge about screening as an important barrier and highlight an opportunity to improve on current

practice by developing tools to provide basic, accessible information about lung cancer screening for patients who may benefit.

CRedit authorship contribution statement

Ilana B. Richman: Conceptualization, Investigation, Formal analysis, Writing – original draft. **Taara V. Prasad:** Investigation, Formal analysis, Writing – review & editing. **Cary P. Gross:** Conceptualization, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Authorship

All contributors to this manuscript met the criteria for authorship. Dr. Richman is responsible for the conceptualization, investigation, formal analysis, and writing—original draft. Ms. Prasad contributed to investigation, formal analysis and writing—review and editing. Dr. Gross contributed to conceptualization and writing—review and editing. Dr. Richman had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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