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Real-world lung cancer screening decision-making: Barriers and facilitators

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ABSTRACT

Objective: To explore 1) attitudes and priorities among physicians and patients that inform shared decision-making about lung cancer screening in real-world settings and 2) physician and patient perceptions of shared decision-making in real-world lung cancer screening (LCS) practice.

Materials and methods: We conducted a qualitative study of 12 physicians and 30 patients meeting LCS screening criteria established by the US Preventative Services Task Force (USPSTF) from two academic primary care practices; one university clinic and one safety net clinic. Interview guides focused on knowledge and attitudes about LCS and experiences with patient-physician communication.

Results: Physicians offered LCS inconsistently and were ambivalent about screening because of potential harms, including false positive results, incidental findings, and radiation exposure. Physicians felt that they were incorporating shared decision-making into screening, although they acknowledged that challenges with screening communication posed barriers to shared decision-making. Patients were generally accepting of lung cancer screening. They expressed fewer concerns about screening-related harms but more personal or emotional concerns related to lung cancer. Patients perceived limited shared decision-making in their encounters, but were generally satisfied with the more physician-directed decision-making process.

Conclusion: Physicians and patients expressed different concerns about LCS and different perceptions about the use of shared decision-making. Findings from this real-world population of screening-eligible patients can be used to inform the design of future interventions to facilitate communication and decision-making tailored to perspectives of both physicians and patients.

1. Introduction

Lung cancer is the second most common cancer in the US and the leading cause of cancer death [1]. Following the results of the National Lung Screening Trial (NLST), which showed a 20% relative reduction in lung cancer mortality with annual low dose computed tomography (LDCT) [2], several professional societies have recommended annual LDCT screening for high-risk individuals meeting age and pack-year criteria [3–6]. Since implementation of this recommendation, screening uptake in the US has been low and variable, with screening rates of 4%–6% among high-risk smokers [7–10].

While the NLST demonstrated reduced lung cancer mortality, implementation of broader screening recommendations involves a complex mix of risks and benefits for patients. Potential harms include radiation exposure and false positive tests resulting in overdiagnosis, overtreatment, potential complications, or anxiety [11,12]. Implementation outside trial settings has shown higher rates of nodule detection and invasive procedures [13,14], heightening concerns about screening harms if inappropriately deployed.

Given the risk-based nature of LCS and the potential harms,

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communication and decision-making is imperative. The goal is to implement appropriate, evidence-based screening using shared-decision making, a process in which clinicians and patients work together to select care plans with the goal that patients understand their options and that patients' preferences guide their decision [15,16]. Guidelines advocate for the use of shared decision-making to determine screening determinations, and Medicare specifically calls for documentation of shared decision-making as part of LDCT coverage requirements [3,17]. However, small studies have demonstrated that shared decision-making is used variably in real-world settings and that patient preferences are inconsistently incorporated into discussions [18,19]. Further, most studies occurring since the U.S. screening guidelines were put into place are limited to settings with robust screening protocols that may not reflect widespread practice [13,18–20].

To determine the appropriate content of screening discussions, it is necessary to assess attitudes toward, barriers to, and facilitators of LCS and the challenges of shared decision-making among patients and providers. Using qualitative methodology, our study aims to address this gap by examining perspectives of both physicians and patients from primary care practices in university and safety net institutions. Specifically, we sought to 1) understand the attitudes and priorities among physicians and patients that inform shared decision-making in real-world settings and 2) explore physician and patient perceptions of shared decision-making in real-world practice.

2. Materials and methods

2.1. Participants and setting

We enrolled physicians and patients from two urban, academic primary care practices in San Francisco, California affiliated with the University of California, San Francisco. One practice was in a university setting and another in the safety net. Although the university did not have a structured program to track LCS candidates and follow-up, providers could order LDCTs and follow results via the electronic health record (EHR). The safety net practice did not have a formal LDCT screening order available, but providers were able to order CT scans of the chest for a variety of indications, including lung cancer screening, upon request.

We recruited a convenience sample of 12 primary care physicians (PCPs) via email from the study practices. All 12 PCPs contacted agreed to be interviewed.

We also recruited 30 current or former smokers who had either received LDCT or met guideline-based screening criteria. These included: age 55–80, a 30 pack-year smoking history, and current smokers or those who had quit within the last 15 years [3]. Patients could not have a prior lung cancer diagnosis or pulmonary nodule. Patients also had to speak conversational English or Spanish. All patients were contacted to confirm pack-year history prior to inclusion in the study.

From the university practice, we used the EHR to identify primary care patients who had undergone screening or were eligible for LCS based on information available in the EHR. We contacted all primary care patients who had undergone LDCT (n = 34) at the time of the study. Of those we were able to reach and met screening criteria (n = 23), ten patients agreed to be interviewed and nine interviews were completed. We also recruited patients identified by PCPs as eligible for screening within the practice (n = 30). Of those who were eligible and could be reached (n = 16), four were interviewed. In addition, we contacted a random sample of patients who likely met screening criteria based on EHR data (n = 97). Of those we were able to reach and met screening criteria (n = 38), 14 patients consented to be interviewed and 13 interviews were completed. Finally, we recruited screening-eligible, unscreened patients from the safety net practice via physician referral and waiting room signs (n = 4).

Of the 30 patients, all but one met the threshold for LDCT based on US Preventative Services Task Force (USPSTF) guidelines; the remaining patient had already undergone LDCT ordered by the PCP at the university practice. PCPs were not matched with patients (i.e. not necessarily providers for the patient participants). Patients received a $40 gift card as compensation for participation.

2.2. Study design

We developed parallel semi-structured interview guides for patients and physicians based on existing literature. Guides were designed to elicit knowledge and attitudes about smoking, lung cancer and LCS as well as information about patient-physician communication related to these topics. Interview guides were revised in an iterative fashion by the research team based on preliminary results. We conducted interviews of PCPs and patients from August 2015–March 2017, with the majority of interviews occurring in 2016. Patient interviews were conducted by research assistants and the principle investigator (MP, AL, CK). Physician interviews were conducted by the PI and two physician members of the research team (ML, MV, CK). Interviews were audio-recorded and transcribed verbatim. All study procedures were approved by the UCSF Committee on Human Research prior to any subject recruitment or data collection, and informed consent was obtained from all participants.

2.3. Data analysis

The team of investigators developed a coding scheme using thematic content analysis [21]. We included a priori themes highlighted in the parallel interview guides and identified emergent themes based on detailed reading of the data. Physician and patient responses were examined separately in order to account for the differing priorities and perspectives of these groups related to screening and to allow different themes to emerge for each group. Three members of the research team completed coding (ML, MP, AL) using ATLAS.ti software. Team members double-coded a subset of the data and met with the research team to determine our initial coding structure. The remaining transcripts were coded independently, with the PI and research team meeting regularly to review the data and revise the codebook in an iterative fashion. Any discrepancies were discussed until consensus was reached.

3. Results

3.1. Demographics

Among the 12 physicians, eight came from the university and four from the safety net (Table 1). There were 11 faculty physicians and one resident, with an average of 13 years in practice (range 2–22). The majority of physicians were female, and half were non-white.

Table 1
Physician Characteristics (n = 12).

Variable	Data
Years in practice	13 (2–22)
Site	
UCSF	8 (67%)
SFGH	4 (33%)
Level of Training	
Attending Physician	11 (92%)
Resident Physician	1 (8%)
Gender	
Male	4 (33%)
Female	8 (67%)
Race	
Caucasian	6 (50%)
Hispanic	3 (25%)
African American	0 (0%)
Asian/Pacific Islander	3 (25%)

Table 2
Patient Characteristics (n = 30).

Physician Charact	Physician Charact
Mean Age (SD, range)	62 years (5.3, 55–74)
Mean Pack-years (SD, range)	46 (18,0, 22–88)
Site	
University	26 (87%)
Safety Net	4 (13%)
Gender	
Male	23 (74%)
Female	8 (26%)
Smoking Status	
Current Smoker	20 (65%)
Former Smoker	10 (32%)
LDCT	
LDCT Screened	10 (33%)
Not screened	20 (66%)
Race	
White/Caucasian	20 (65%)
Hispanic/Latino	2 6%)
African American	6 (19%)
Asian/Pacific Islander	2 (6%)
Native American	1 (3%)
Education	
Less than high school	2 (6%)
HS Grad/GED	5 (16%)
Some college/ Associates	9 (29%)
Bachelors or Graduate Degree	10 (32%)
Did not say	5 (16%)
Employment	
Employed	6 (20%)
Disability	11(35%)
Retired	9 (29%)
Unemployed	4 (13%)
Did not say	1 (3%)

Of the 30 patients, 26 were from the university and four were from the safety net practice (Table 2). 33% underwent LDCT screening, all from the university practice. The average patient age was 62 (standard deviation 5.3, range 55–74). 65% were white, 19% were African American, and 6% were Latino. Mean pack-year history was 46 years (standard deviation 18,0, range 22–88). The The majority of the patients were male (74%) and current smokers (65%). Seven of nine who had undergone LDCT were currently smoking.

3.2. Physician perspectives

3.2.1. Ambivalence towards screening

Although all the physicians were aware of LCS guidelines and most could describe components and/or data supporting the guidelines, they were inconsistent in their LCS practices. At the university practice, all physicians had either offered or considered LDCT for eligible patients, whereas at the safety net site, most physicians did not offer screening. Physicians cited several reasons for not screening universally. These included time, competing priorities, and system capacity for screening, particularly for the safety net physicians.

While a few were more enthusiastic, many physicians expressed ambivalence about screening recommendations, largely related to the quality and maturity of evidence. However, the consensus among those for whom LDCT was available was to consider screening, citing guideline recommendations: *"I know that the finding was positive in the trial. I also know that we often find positive findings for cancer screening trials that then wash out over time for a variety of reasons, so I'm really cautious. And if asked, my bias is against screening for using this modality right now, but I try to be the good soldier and present it as the USPSTF recommendation"* (Physician, university practice).

Physicians in both settings were also ambivalent about whether LCS was the best modality for lung cancer prevention. One said, "*I honestly feel like bang for buck, if I had to pick what mattered to me, it would be figuring out how to buff up our smoking cessation effectiveness"* (Physician, university practice). In this way, physicians questioned whether implementing a new practice with an evolving evidence base was the best use of time when it did not address the root cause of the issue.

The safety net practice did not have a formal LCS order or protocol in place, but physicians were able to order chest CT scans if they opted to screen patients. Physicians expressed similar concerns to those in the university setting, but there was a perception of greater health system-related obstacles to care that were more prominent in the safety net: *"Right now I'm not screening my patients … I worry a little bit about the fact that if we were to screen every single patient who is eligible every year* that *might overwhelm radiology. We don't seem to have a good system in place right now"* (Physician, safety net).

3.2.2. Concerns about screening harms

Physicians' main concerns about screening harms centered on two major areas: 1) false positive or incidental findings and 2) radiation exposure. PCPs in both settings were most concerned about the high rate of false positive and incidental findings generated by screening. Concerns mainly stemmed from potential harms, including morbidity and risks of subsequent workup: *"You find something that you're not looking for. And you engage in a workup that can be highly morbid to the individual without definite benefit … I think that on balance risks and benefits, I'm reluctant to say definitively that it's a good thing"* (Physician, university practice). The false positive rate coupled with patient and system barriers to follow-up also created reluctance to screen, particularly among safety net physicians. Further, the social complexities of patients made follow-up more burdensome, leading some physicians to screen less. "*The issues with some of my smokers, at least, are fairly complex. They require a fair amount of negotiation, not just with the patient but with the whole system … that makes me a little wary of saying let's just screen"* (Physician, safety net).

Physicians were also concerned about patient stress or anxiety related to incidental findings and over-diagnosis. Particularly in the context of their own ambivalence, there was a heightened sensitivity to patient stress: "*I tell them there's a chance that they might need to do a biopsy to actually see if it's cancer or not, and obviously that scares people. And then not even to go into the whole, and it might be nothing, so we might've put you through the risk for nothing. I mean, I don't really phrase it like that, but I don't hide my emotions very well, and so that might come across inadvertently" (*Physician, university practice).

Finally, physicians at both sites were concerned about the cumulative harm of radiation exposure for ongoing annual screening: "*It sounds like a great thing for a year or two. But if you're really doing it for decades, that seems like a lot of radiation*" (Physician, safety net). Although concerns about radiation ranged, the majority of physicians ultimately accepted the risk of radiation in the face of other benefits: *"It definitely raises the concern for just the exposure to radiation … But for me, I'm still impressed with the overall benefit of incorporating the screening on mortality so, I think it overrules everything else" (*Physician, university practice).

3.2.3. Experience versus data

Physicians reported balancing the tensions between data and personal experience in their medical decision-making: "*I feel evidence is one thing and then anecdotal experience is another, which is also a very powerful driver of practice. I certainly have had patients that we have found something incidentally. That's one of the reasons that does drive me with those folks who have more intense histories than most of our patients for me to at least have the conversation with them"* (Physician, safety net).

Physicians also cited experiences with prior screening tests as a driver of current practices. Some mentioned that one of the challenges of implementing new screening tests was not just the lack of long-term data, but also the lack of experiences to draw from in counseling patients: "*I think this is very new territory, and I think a lot of what drives our practice is what we experience with patients … And so, I think I'm gonna have to give this a couple of years before I really have a good way to*

approach it" (Physician, university practice).

3.2.4. Risk communication ad shared decision-making

When asked about incorporation of shared decision-making – including discussions of risks and benefits and elicitation of patient preferences – physicians reported presenting balanced conversations, focusing on the benefits of early detection but also limitations of the test. Some physicians were concerned that despite discussion, patients did not really understand the issues at stake: "*The patient was less concerned than I was about finding something else. The patient was interested in finding everything … But they haven't seen, in most cases, all of the harm caused by the medical system that I have, and so that's why they tend to favor knowing more"* (Physician, university practice).

The consensus among physicians was that screening decisions were made in partnership with patients, although some acknowledged playing a larger role in the decision-making process for those with lower health literacy. *"I do my best to explain it in laymen's terms. Certainly, in situations where I get the sense that they don't fully comprehend the risk, I do tend to be a little more directive with those patients about my recommendations"* (Physician, safety net).

PCPs also perceived differences among patients in their preferences for handling uncertainty, but noted that regardless of patient preference, the limitations of LDCT were the most challenging aspect of risk communication for them. *"For patients who want 100 percent the answer, it's very difficult to make them understand that there's no screening test that's perfect … For patients who don't want to know they have [cancer] … it's very difficult to persuade them to go for the testing because the testing is not perfect. So, I guess the main stumbling block is that there's no perfect test for lung cancer"* (Physician, university practice).

3.3. Patient perspectives

3.3.1. Acceptance of screening

The majority of patients, including those who had not undergone screening, found LDCT acceptable. Patients mainly viewed LDCT as a tool for prevention and early detection as well as reducing anxiety about cancer: "*If I know I have something that could potentially kill me, I'd like to know now so I could just take care of it and do what I have to do – it would drastically change the course of my life"* (LDCT-screened patient, university practice). Patients reported few screening barriers, and those that were reported were generally practical in nature. One third of patients reported no barriers, and the consensus among the remaining participants was that the main barrier was cost, with most patients across sites willing to undergo LDCT if covered by insurance.

3.3.2. Minimal concerns about screening harms

In general, patients were not deterred by false positives or overdiagnosis. Patients typically understood false positives as inherent to the screening process and preferred the risk of a false positive to the risk of missing cancer: "*Well on one hand you've got the potential for a false positive and on the other hand you have not doing anything at all and if you get it waiting for it to show up on an x-ray and that's scarier … I'd rather have better odds going in even if there's a risk of a false positive*" (LDCT-screened patient, university practice). The majority viewed follow-up as low risk and saw this as a means of bringing greater clarity to their diagnosis: *"If they have to take a biopsy, they're only taking a little snip … I'm not concerned about that. Just the fact that they think they found something means they're looking hard"* (Unscreened patient, safety net).

In terms of radiation exposure, patients were generally aware of radiation but had limited knowledge about specific risks. Some cited prior radiation exposure – either from imaging tests or even in the environment – as evidence for the benign nature of radiation: "*[Radiation] doesn't worry me. I have had a lot*" (Unscreened patient, university practice). Patients also trusted their physicians to order safe tests and use the lowest amount of radiation possible: *"It's the 21 st century, and it's so low. I mean we get X-rays, and I'm sure it's made as safe as possible"* (Unscreened patient, university practice).

3.3.3. Personal and emotional concerns

Many patient concerns focused on the personal and emotional aspects of lung cancer, and these concerns were important motivators for screening, particularly fear of the disease. Patients described lung cancer as severe, deadly, and uncomfortable. There was fear related to poor prognosis and limited therapeutic options: *"I think it is a scary cancer in terms of the prognosis and the limits of treatment"* (LDCT-screened patient, university practice). Fear was also due to perceived unpredictability of the disease: "*Lung cancer, you haven't got a clue. Somebody comes up behind you and hits you with a baseball bat. That's really lung cancer. It's a death sentence*" (Unscreened patient, safety net). A number of patients were familiar with lung cancer through experiences with friends or family members: "*I have seen it in my friends in family. For me it is terrible to see them with the oxygen tank. In fact, my sister-in-law recently died from lung cancer, its extreme suffering because of smoking. She was already dying … and she was still asking for a cigarette"* (Unscreened patient, university practice).

Some patients also expressed fear of treatment, particularly chemotherapy. One reported: *"That the treatment is worse than the disease is one idea, or feels worse than the disease, even though it may increase my lifespan maybe two or three years. That's the main reason that they do these extreme things to your body, I believe"* (Unscreened patient, university practice). However, few ultimately reported being deterred from screening by these concerns.

We also saw fatalism towards lung cancer among participants. For some, this contributed to fear of cancer: *"Lung cancer is the worst cancer you could have because I think you go quicker with lung cancer … If the Lord is ready for me to go, he's going to take me. If he's not, I'll still be here. That's how I feel about that"* (Unscreened patient, university practice). A few were fatalistic towards prevention and used this as a justification to continue risky behaviors: "*Of course I don't want to shorten my life but it's like if I don't smoke, I still shorten my life because I'm going to stress myself to death. So either way, it is what it is. That's how I feel. It is what it is. It's like if I stress on it, I'm going to die. If I don't stress on it and it's fine"* (Unscreened patient, university practice). Overall, fatalism helped mitigate stress related to lung cancer for some patients but was rarely given as a justification for avoiding screening.

3.3.4. Risk communication and shared decision-making

Few unscreened patients reported discussing LCS with their doctors. Among the screened patients, the majority reported brief screening discussions highlighting benefits of early detection with minimal discussion of risk. *"[My doctor said] just that it was a good precautionary measure, but he didn't explain too much else about it*" (LDCT-screened patient, university practice). The consensus among patients was that PCPs made the recommendations. Patients relied on physicians to distill decision-making down and provide them with a tailored and clear explanation of the risks and benefits of the test. *"I would need the help of the doctor to explain everything to me in a way that I can understand it and be completely frank with me"* (Unscreened patient, safety net practice). However, patients were generally satisfied with the amount of information and trusted their physicians to order safe and effective tests.

4. Discussion

The goal of LCS is to implement appropriate, evidence-based screening using shared-decision making in risk-appropriate patients to maximize benefits and minimize harms. In our study, we elicited physician and patient perspectives about screening and communication. We found that physician and patients approached screening from different perspectives and expressed different concerns, particularly related to screening harms. Further, shared decision-making was perceived differently by the two groups, with physicians reporting more robust discussions and patients perceiving that decisions were largely

made by physicians.

Our results mirror literature that patients are frequently enthusiastic about screening, emphasized the benefits and minimized the risks, and were influenced by emotional factors such as fear and fatalism. Similar responses have been seen among VA patients [21] and among a general sample of high-risk smokers prior to the USPSTF recommendations [22]. Patients in our study were also motivated to screen to reduce uncertainty given their worries or fears about lung cancer, as has been described previously [23]. The physician participants were more reticent towards screening and placed greater emphasis on potential harms. They cited the data and the fact that the both the studies and the guidelines on which they were based were new at the time. However, we also found that their screening decisions and communication were influenced by personal experiences and the challenges of translating evidence into practice. Particularly in health care settings without structured screening programs, some of the challenges inherent to screening may be even greater as providers may have limited access to expert consultation or less support in handling the consequences of positive LDCTs.

Although shared decision-making prioritizes inclusion of patient preferences, it also requires accurate understanding of the benefits and harms. Prior literature has demonstrated that patients have inaccurate beliefs about the effectiveness of screening and potential risks [24]. Therefore, it is imperative that communication around preventive screening balances the conveying of information with elicitation of patient preferences. Although physicians reported having more balanced and extensive discussions, this was not reflected by patients, who reported that providers largely made recommendations without taking into account their preferences. This finding mirrors the results of prior literature, including several recent studies that have demonstrated limited use of shared decision-making and provision of only minimal information on the harms of screening [19,25]. Physicians in one study cited similar barriers as were seen in our analysis including time, competing priorities and limited patient understanding [19].

These results add to the literature by providing a lens into real-world discussions about LCS among diverse patients and in diverse settings. Much of the literature around screening beliefs, communication, and shared decision-making comes from the Veteran's Administration, which has implemented a robust screening program within their population, or within other structured screening programs [18,19,21]. In our study, we examined patients from diverse ethnic backgrounds as well as diverse settings, including two academic practices in a university and safety net system. Since neither practice had a structured screening protocol, they are likely to reflect the diversity of screening practices that exist in broader settings without programs in place. Further, the lack of a structured screening program may influence physician's attitudes towards uptake of screening recommendations and likely adds to uncertainty and concern about LCS-related harms. This was particularly true in the safety net setting, where providers had less certainty about access to specialists and follow-up. Although our sample from the safety net was small, it will be important to incorporate safety net settings into future studies to ensure that screening guidelines are implemented in an equitable manner.

Our study has several important limitations. First, it occurred at two sites in a single city. Further, our physicians and patients were not dyads, so their differing perspectives may, in fact, reflect different experiences. Our study also took place over a time period after USPSTF guidelines came out and LCS practices were evolving. In this period, physicians were developing practices and patients may have less knowledge about LCS compared to other screening tests. However, this also presents an opportunity to explore the thought processes that underlie screening communication practices. Finally, in our qualitative study, the population was not representative of all perspectives and experiences. Physicians and patients included in the study were a non-random sample from two clinics whose attitudes and experiences may not have been reflective of all physicians or patients in the clinic or the general population of PCPS and patients eligible for lung cancer screening. For example, the majority of patients were white and English- or Spanish-speaking, so may not reflect the full diversity within our practice setting. Also, the majority of the patients in this study were college educated or higher, which is not the case among smokers across the U.S. and may limit generalizability. However, we looked at a range of perspectives among both physicians and patients that likely reflect the variety of experiences LCS in real-world settings.

5. Conclusions

In conclusion, both patients and physicians were considering similar issues related to LCS but viewed them differently. Physicians were ambivalent about LCS and largely concerned about potential screening harms. Patients were less concerned with screening harms and prioritized personal and emotional concerns related to lung cancer that often motivated their decisions about screening. Physicians and patients had different perceptions about the level of shared decision-making that occurred in practice. Findings from this real-world population of screening eligible patients can be used to inform the design of future interventions to facilitate communication and decision-making tailored to perspectives of both physicians and patients. Greater integration of structured screening programs may help mitigate concerns about harms and allow for a more systematic approach to screening and communication.

Declaration of interest

The authors declare no potential conflicts of interest.

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