Patients' Attitudes Regarding Lung Cancer Screening and Decision Aids

A Survey and Focus Group Study

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Abstract

Rationale: Little is known about vulnerable patients' perceptions and understanding of, and preferences for, lung cancer screening decision aids.

Objectives: To determine, in a low-income, racially diverse population, (1) participants' experience, preferences, and reactions to web-based and paper decision aids, and (2) their understanding of harms and benefits of lung cancer screening.

Methods: We enrolled outpatients at an urban county hospital in six focus group discussions that included review of a web-based and a paper-based lung-cancer screening decision aid. Participants completed surveys before and after the focus groups.

Measurements and Main Results: Forty-five patients participated (mean age, 61 yr; 76% current smokers; 24% former smokers); 27% had not completed high school; 50% had an annual income not exceeding \$15,000; 42% were nonwhite; and 96% reported chronic illness requiring at least three health care visits yearly. Comparing the proportion with correct answers on pre- and

postsurveys, participants' understanding of lung cancer screening increased, particularly of the harms of screening including the potential for false positives, extra testing, and complications. However, after conclusion of the focus groups, more than 50% believed that screening lowered the chance of getting lung cancer. Five major themes emerged from qualitative analyses. Participants (1) were not aware of the purpose of lung cancer screening; (2) wanted to know about the benefits and harms; (3) believed physicians need to communicate more effectively; (4) found decision aids helpful and influential for decision-making about screening; and (5) wanted the discussion to be personalized and tailored. Participants expressed surprise that the magnitude of their lung cancer risk and benefits of screening were lower than anticipated.

Conclusions: Vulnerable patients find lung cancer screening decision aids helpful and generally show increased knowledge after reviewing decision aids, particularly of harms. Our results can inform future implementation efforts.

Keywords: lung neoplasms; early detection of cancer; health care disparities; decision support techniques; qualitative research

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The National Lung Screening Trial (NLST) demonstrated that low-dose chest computed tomography (LDCT) is associated with decreased lung cancer mortality among high-risk smokers (1) and is becoming the standard of care (2, 3). Shared decision-making regarding screening for lung cancer is either recommended or required (4, 5), and certain insurance programs including Medicare will not pay for LDCT screenings unless shared decision-making is documented and uses one or more decision aids. Shared decision-making is a collaborative process that allows patients and providers to make health care decisions together, taking into account patients' values and preferences along with the best clinical evidence available. Discussion and documentation must incorporate the benefits and harms of screening, smoking cessation, and outcomes (6, 7).

As lung cancer screening is actively translated into clinical practice, implementation in populations poorly represented in clinical studies including the NLST needs to be considered (8). Few studies have addressed implementing lung cancer screening and using decision aids in vulnerable populations—defined by race/ethnicity, education, and socioeconomic status (9–13). However, the burden of smoking and lung cancer can be disproportionately high in these groups (14, 15).

Therefore, we explored how to foster shared decision-making within this patient population and evaluate whether patient-centered communication using decision aids improves understanding of lung cancer screening benefits and harms. In a mixed-methods approach, we conducted focus groups with low-income, vulnerable smokers. Participants completed surveys before and after focus groups assessing knowledge and attitudes regarding lung cancer screening.

Methods

Participants and Setting

We enrolled outpatients from Harborview Medical Center, an urban county hospital in Washington State that serves as a health care safety net for low-income individuals. The University of Washington Institutional Review Board approved the study; participants provided written, informed consent. Six focus groups were

conducted from March to July 2015. To be as inclusive as possible, we followed the National Comprehensive Cancer Network criteria for lung cancer screening and recruited subjects who were aged 50–74 years and current or former smokers for at least 20 pack-years. We also recruited participants age 50 years or more in our final two focus groups in whom incidental pulmonary nodules had been discovered; 6 of 14 had less than 20 pack-years of smoking. Exclusion criteria included cognitive or language limitations (e.g., expressive language limitations, non-English speaking) or known malignancy (except nonmelanoma skin cancers).

To recruit participants with diverse backgrounds, we recruited six focus groups: four groups from an adult medicine clinic ($n = 31$) and two from an HIV primary care clinic ($n = 14$). Because no new themes were noted to emerge by the focus group facilitator during discussion with the fourth group compared with the earlier groups, we recruited participants who had an incidental nodule on chest CT within the last year to form the last two groups ($n = 14$). We theorized that these participants might have different opinions and knowledge given their prior experience. No participants had undergone an LDCT for lung cancer screening, as our institution has not implemented a formal screening program.

To identify potential participants meeting inclusion criteria, we screened the electronic medical record for age and smoking status (pack-years were not recorded reliably), and contacted potential participants. In total, the research coordinator (S.S.) attempted to contact 243 patients via telephone. Approximately 30% could not be reached (disconnected telephone or did not return calls), 35% declined participation before pack-years of smoking could be confirmed, and 35% were interested in the study. Of those interested in participating, nearly 25% did not ultimately meet inclusion criteria (mainly due to <20 pack-years of smoking). In total, 67 agreed to participate, and 45 arrived as scheduled and participated in a focus group that was held at Harborview Medical Center. Participants received a \$25 cash incentive and were reimbursed for transportation.

Decision Aids

Two decision aids informing patients of the process, benefits, and harms of lung

cancer screening were used for each of the group discussions: (1) a web-based tool (www.shouldscreen.com) developed at the University of Michigan (10, 11) that includes information on lung cancer, screening, harms and benefits, and a personalized 6-year risk calculator; and (2) an educational paper pamphlet developed by the Veterans Affairs (VA) Health Administration (http://www.prevention.va.gov/preventing_diseases/screening_for_lung_cancer.asp) (4), which includes the harms and benefits of lung cancer screening, eligibility, and a pictogram explaining benefits and harms of screening using NLST results. The paper pamphlet materials were written for a seventh-grade reading level, and all complex medical terms and numerical descriptions were reviewed by a multidisciplinary VA committee that included experts in health communication. The web-based decision aid was designed for an eighth-grade reading level, and was vetted by experts from the University of Michigan Center for Health Communications Research. The web-based decision aid was tested in a convenience sample of 60 current and former smokers from the Ann Arbor area; 22 of them did not finish college.

Each group reviewed the web-based tool first, with each participant using a personal computer. Next, the group of participants moved into a conference room and reviewed the paper pamphlet as part of the discussion. Our goal was to assess reactions and responses to these two decision aids as initial steps to inform further usability testing and implementation in similar populations.

Surveys

Participants self-completed brief surveys before and after the focus group regarding attitudes and knowledge of lung cancer screening (see the online supplement). Questions were adapted from prior studies (9–11). Given the small sample size, answers to questions were frequently dichotomized for analysis. We assessed the overall percentage of questions regarding benefits and harms that were answered correctly, grouping “unsure” answers with incorrect responses. Answers about attitudes regarding lung cancer screening grouped “strongly agree” or “agree” together compared with “undecided/unsure,” “disagree,” or “strongly disagree.”

Discussion Guide

A discussion guide was used for all focus groups (*see* the online supplement). This guide was piloted in a patient interview followed by a small patient discussion group before being used in the subsequent six focus groups. An experienced facilitator with a Ph.D. in social psychology (L.M.R.) led each approximately 1.5-hour-long group. First, participants completed presurveys and were next given access to a personal computer to examine the web-based decision aid for 10–15 minutes. Then, focus group discussions began with an explanation of LDCT scans and lung cancer screening. The facilitator guided discussion of participants' prior knowledge of lung cancer screening and current recommendations for high-risk smokers, followed by an overview of the paper-based decision aid. Open-ended questions were posed about decision aid clarity, balancing potential benefits and harms of screening, and changes in thinking due to gained understanding from the decision aids.

The facilitator next queried participants' understanding of difficult concepts related to lung cancer screening, including "positive CT," "false positive," and "overdiagnosis." Participants were asked their understanding of each term, whether knowledge of these potential outcomes changed their thinking about screening, and how they would like these concepts explained. Participants were asked about their preferences for printed versus web-based decision aids, and the method/timing of their delivery. Focus groups concluded with questions regarding communication preferences about lung cancer screening, including how providers might use decision aids with their patients.

Analysis

Pre- and postsurvey responses were verified using double-data entry. Cochran–Mantel–Haenszel and Friedman tests were used to test the hypothesis that the pre- and postintervention binary and ordinal paired responses were in agreement, respectively. *P* values were two-sided and considered statistically significant at less than 0.05. All statistical analyses were performed with SAS version 9.4 (SAS Institute Inc., Cary, NC). There were no statistically significant

differences in the quantitative survey results between participants if they had an incidental pulmonary nodule identified or not, or if they were screen eligible or not, with the exception that participants who were not eligible for screening endorsed more concern about radiation exposure with screening. Given the similarity of responses, the data were combined for analyses.

Focus groups were audio-recorded and transcribed verbatim for qualitative analysis. The research team concluded that saturation was achieved when all ideas expressed were repetitive with those expressed in previous groups; thematic saturation was achieved during the fourth group. Because there were no differences in the qualitative themes that emerged based on participant characteristics or in those with incidental pulmonary nodules identified, we combined all results for analyses. We conducted iterative rounds of analysis using immersion–crystallization techniques to come to agreement on key themes (16). Initially, two investigators (L.M.R., E.K.) independently reviewed transcripts to develop a list of key themes, and then compared their interpretations and resolved differences of opinion about the meaning of specific passages. Next, the lead investigator (K.C.) reviewed transcripts and revised themes. Finally, the initial two investigators re-read the transcripts to code theme frequency and identify quotations exemplifying themes.

Results

Participant Characteristics

The six focus groups had seven to nine participants each (total *n* = 45), with 71% men and 29% women with diverse smoking histories (Table 1). One-half of the participants reported annual incomes not exceeding \$15,000, 42% were nonwhite race, and 27% had not completed high school. Almost all participants (96%) reported chronic illness requiring health care visits at least three times yearly, and 60% had previously undergone a chest CT.

Surveys included items about preferences for receiving health information. When asked, "How often do you have problems learning about your medical condition because of difficulty understanding written information?" 80% replied in the range from

"occasionally" to "always." The preferred method for receiving health information was directly from their doctor (71%) or another health care professional (44%); written materials were more popular (38%) than web-based materials for health information (20%).

Quantitative Survey Results

Participants demonstrated improved knowledge about lung cancer screening after reviewing two decision aids and spending 1.5 hours in a discussion group (Table 2; and *see* Table E1 in the online supplement). Most notable was improvement in knowledge about possible harms associated with screening; the proportion answering these items correctly increased from 69 to 93% overall (*P* = 0.002), calculating an index of the percentage of correct responses. However, knowledge of benefits did not change as much. More participants endorsed that screening lowered one's chances of "getting lung cancer" at the end of the focus group discussions, increasing from 25% before to 50% after focus group attendance.

Most participants who entered the focus group agreed or strongly agreed with the statement, "I want to be screened for lung cancer," with a similar proportion endorsing this on postsurveys (77 vs. 73%, *P* = 0.80; Table 3). There was no significant change in subjects' perception of their own lung cancer risk or the feelings of worry that would result from an abnormal LDCT scan. Few participants agreed that if they had a normal LDCT scan they could "continue to smoke without worrying," although there was a nonsignificant increase in participants who endorsed this response (7 vs. 11%; *P* = 0.16).

Qualitative Focus Group Results

Focus group discussions centered on the question "What do patients think about decisions surrounding lung cancer screening?" Five themes emerged from the qualitative analysis; exemplary quotes were identified (Table 4, Table E2). Discussions concluded by asking participants about how decision aids might be used in practice (Table 5).

Theme 1: Patients Are Not Aware of the Purpose of Lung Cancer Screening

Participants were initially bewildered about the purpose and differences between LDCT

Table 1. Participant characteristics

Characteristic	Response
Age (yr), median (IQR)	61 (57–61)
Female, n (%)	13 (29)
Race, n (%)	
American Indian or Alaska Native	1 (2)
Asian	2 (4)
Black or African American	14 (31)
Native Hawaiian or other Pacific Islander	2 (4)
White	26 (58)
Ethnicity: Hispanic, n (%)	1 (2)
Currently smoke cigarettes, n (%)	
Every day	25 (56)
Some days	9 (20)
Not at all	11 (24)
Years since quitting smoking, n (%)	
Still smoking	29 (64)
Cigarettes per day, median (IQR)	20 (13–30)
Within the last 12 mo	4 (9)
1–5 yr ago	4 (9)
5–15 yr ago	4 (9)
>15 yr ago	4 (9)
Pack-years of smoking, median (IQR)	37 (23–54)
Eligible for lung cancer screening per USPSTF criteria, n (%)	20 (44)
Highest grade completed, n (%)	
Eighth grade or less	2 (4)
Some high school	10 (23)
High school graduate or equivalent	13 (30)
Some college	12 (27)
College graduate	4 (9)
Graduate or professional school	3 (7)
Annual household income, n (%)	
<\$5,000	4 (9)
\$5,000–\$15,000	18 (41)
\$15,001–\$30,000	6 (14)
\$30,001–\$50,000	4 (9)
>\$50,000	4 (9)
Don't know	3 (7)
Prefer not to answer	5 (11)
Health insurance,* n (%)	
Private/HMO	5 (11)
Medicare	30 (67)
Medicaid	19 (42)
Self-pay	3 (7)
Other	4 (9)
Don't know	2 (4)
None	1 (2)
Do you have a chronic illness that requires you to see a doctor or nurse at least three times a year? Yes, n (%)	43 (96)
Have you ever had a CT scan? n (%)	
Chest	27 (60)
Other	12 (27)
No	5 (11)
How often do you have problems learning about your medical condition because of difficulty understanding written information? n (%)	
Always	3 (7)
Often	6 (13)
Sometimes	14 (31)
Occasionally	13 (29)
Never	9 (20)
How often do you find numbers, figures, or graphs to be useful? n (%)	
Never	1 (2)
Rarely	4 (9)
Sometimes	24 (53)
Fairly often	16 (36)

(Continued)

screening versus diagnostic examinations. When asked, “Before you came today, what did you know about lung cancer screening?” participants frequently responded with “Nothing,” “Very little,” “It hadn’t really been brought up,” and “It’s new to me too.” Participants who had experienced a similar screening examination for other diseases were more confident expressing some knowledge.

Theme 2: Patients Want to Know about the Benefits and Harms

Most participants agreed patients should be informed of both benefits and harms: “I would want to know [the pros and the cons].” Participants had a very clear understanding of the benefits of screening: “Catch it in time so you can be treated for it.” Most participants understood a false positive, once it was explained using decision aids: “Yeah. You may not even have cancer.”

Participants also understood there are potential harms that could result from screening: “Those additional procedures can cause a great deal of harm.”

Participants had difficulty understanding the concept of overtreatment, but after an explanation, responded, “Yes, I’d like to know that.” A small number of participants were unsure, however, whether their doctors would, or should, explain screening harms: “I don’t know whether my doctor would tell me the risks....And quite frankly, if you look at your handout that you get when you get your medication, my God, I’d never even take an aspirin probably. So I can see why.”

Participants were mixed on the appropriate timing for education about false positives and overtreatment, with many believing doctors should consider the impact of too much information too early. Others wanted as much information up front as possible, stating, “Being ignorant is torture to me,” and “The more you know the better decisions you can make.”

Theme 3: Physicians Need to Communicate Effectively to Patients

Message delivery was as important as the content delivered. Participants did not want physicians to “dance around it” or “beat around the bush,” preferring the “straight dope” approach. Although participants could not articulate the precise wording physicians should use when explaining harms and benefits, the majority expressed

Table 1. (Continued)

Characteristic	Response
How do you like to receive health information,* n (%)	
Web-based (on computer, smart phone, tablet)	9 (20)
DVD (to watch at home or in doctor's office)	4 (9)
Written materials on paper (brochure)	17 (38)
Prefer to talk directly with doctor	33 (73)
Prefer to talk directly with other health care professional (nurse, social worker, other)	19 (42)
Other	1 (2)

Definition of abbreviations: CT = computed tomography; HMO = health maintenance organization; IQR = interquartile range; USPSTF = U.S. Preventive Services Task Force.

*Participants could select more than one choice.

that a good bedside manner was of key importance during information delivery, communicating with patients “as a human being” and “not an ATM machine.”

Participants felt strongly about “*putting it in plain English*,” and avoiding “*the doctor’s language*.” Some patients preferred the term “false alarm” to “false positive,”

and reflected that the term “positive” could create confusion: “Positive means different things to different people. The word positive can be misconstrued.”

In addition, participants who currently smoked articulated wanting to learn from their physicians, but requested they avoid “*blaming the victim*.” Smokers did not want to be “beat up” because of their smoking habits and several believed that other lung cancer risk factors deserved more emphasis.

Theme 4: Decision Aids Are Helpful and Influential in Decision-Making

Participants found the decision aids informative: “*Y’all have done a very good job of putting this pamphlet together. I tell you, that got my eyebrows way up.*” After

Table 2. Participant knowledge regarding lung cancer screening at baseline and after attending a 1.5-hour focus group and reading two decision aids; n = 45 participants

True/False Questions	% Choosing Response Marked as “True”		P Value*
	Baseline	After Focus Group and Reading Two Decision Aids	
Factors that increase chances of developing lung cancer:			
Smoking	98	100	0.32
Family history of lung cancer	67	74	0.65
COPD	64	62	0.53
Age, yr	42	46	0.65
Getting screened for lung cancer involves having a CT scan yearly for at least 3 yr	20	63	<0.001
A “false-positive” chest CT scan is when the scan shows that you have a cancer when you do not	52	82	0.003
All cancers found in the lung will grow to be life-threatening	34	20	0.083
All smokers should be screened for lung cancer	82	64	0.033
Possible benefits of lung cancer screening:			
It lowers your chances of getting lung cancer	25	50	0.004
It can cure cancer	5	9	—
It lowers your chances of dying from lung cancer	69	84	0.21
It lowers your chances of developing lung nodules	32	23	0.096
Overall understanding of benefits of lung cancer screening	82	84	0.65
Possible harms of lung cancer include:			
You may find some things in your lungs that are not cancer but would need an extra test to check	68	88	0.013
You may need to get an extra test, which can cause complications	28	82	<0.001
There are no harms associated with screening	52	19	0.002
Overall understanding of possible harms of lung cancer screening	69	93	0.002
Chest CT scans for lung cancer screening:			
Can show a cancer in your lung when you do not have one	24	72	<0.001
Can miss a cancer in your lungs	42	56	0.17
Result in exposure to radiation	33	67	<0.001

Definition of abbreviations: COPD = chronic obstructive pulmonary disease; CT = computed tomography.

*Cochran–Mantel–Haenszel (CMH) test (general association) for clustered dichotomous response data.

Table 3. Participant attitudes regarding lung cancer screening at baseline and after attending a 1.5-hour focus group and reading two decision aids: n = 45 participants

	% Strongly Agree or Agree*		P Value†
	Baseline Strongly Agree or Agree (%)	After Focus Group and Reading Two Decision Aids Strongly Agree or Agree (%)	
Statement:			
I want to be screened for lung cancer	77	73	0.80
I want to follow my doctor's recommendations	96	100	0.16
I am at risk for lung cancer	74	69	0.32
I am worried about the additional tests that would be necessary if the scan found something	58	56	0.81
Having an abnormal result on the chest CT scan will cause me to worry	61	51	0.17
I am worried about exposure to radiation from the CT scan	27	29	>0.99
A normal CT scan will make me less worried about developing lung cancer	66	73	0.41
If my CT scan is normal, I can continue to smoke without worrying	7	11	0.16

Definition of abbreviation: CT = computed tomography.

*Dichotomized response created from Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree).

†Cochran-Mantel-Haenszel (CMH) test (general association) for clustered dichotomous response data.

discussion and review of the decision aids, understanding of lung cancer screening improved. The decision aids conveyed new and surprising information, particularly that the magnitude of their risk of lung cancer as calculated using the online decision aid was lower than expected. In addition, numerous participants expressed concern about the number of false positives and that the magnitude of benefit in detecting true disease was lower than anticipated. Although most participants initially interested in lung cancer screening remained so after discussion, the decision aid material made some question whether to undergo screening.

Most participants wanted someone to review the decision aid with them, responding with a resounding “No,” when asked whether they preferred reading the decision aid alone. Participants’ comments included “I don’t understand it that well,” or “Some words were a little too big for me.”

Theme 5: The Discussion Must Be Tailored to the Patient

Participants felt strongly that consideration of patients’ unique personalities, preferences, and experiences is extremely important in the discussion about lung cancer screening. Consequently, there was no consensus of the “right” way to educate patients on the benefits and harms of lung

cancer screening. Participants wanted differing levels of information from their doctor. Some wanted as much information as possible: “Be forthright and upfront...don’t sugarcoat it,” whereas others wanted less: “I think too much information is worse than not enough. Because if you have it all thrown to ya and then you’ve got to decide what am I gonna look at, what am I gonna look at, the tendency is to stop. Not look at anything. And that would be worse.” Further, other patients wanted to make decisions with their doctor, whereas others believed they would take their doctor’s advice: “Well, if my doctor told me to do it, I’d do it.”

The doctor–patient relationship was key to understanding this balance, with one participant expressing, “By now the doctor should know his patient well enough. What type of information can this patient handle? How fast, in what language?” The importance of tailoring the discussion to the individual was a common request from patients: “What [my doctor] did for the last person....he can’t just do that for [me]. He should know you at that point.” Another participant stated, “When it comes to the doctor, he needs to know his patient. You have to handle it differently with somebody taking antidepressants than somebody who’s not.”

Potential Implementation Considerations

In open-ended questions considering decision aids, format was critical: many participants preferred the pamphlet over the web-based tool. Several participants were uncomfortable using a computer, or had never tried. Between two and six participants in each group needed assistance with the computer or navigating the web-based tool.

Despite different format preferences, participants agreed that the web-based risk calculator and the paper pictogram were both helpful and aided their understanding. Many participants preferred taking the pamphlet home to read before their appointment. Participants did not agree which health professional would ideally review the decision aid with them, with some preferring the doctor, others a nurse or nurse practitioner, and one suggesting “a person [volunteer] that has been through it.”

Discussion

In this study, quantitative and qualitative data indicate that decision aid–facilitated discussions helped to improve participants’ understanding of harms and benefits of lung cancer screening. Although many participants had undergone a chest CT,

Table 4. Themes and select subthemes of patient attitudes regarding decision aids and lung cancer screening

Theme	Subtheme	Representative Quotes (Participant #)
Patients are not aware of the purpose of lung cancer screening	Doctor hasn't mentioned it/new information	"I haven't heard [of lung cancer screening]." (P #4) "I've never heard anything about it." (P #18) "You know at a certain age you hear about the tests. The colon tests....But no one ever puts lung cancer screening tests in that group, you know. If it was put like that, more of us would have heard of it." (P #15)
	Confused with diagnostic CT scans	"The doctor said 'We're gonna screen you for cancer. We wanna make sure that little nodule isn't going anywhere.'" (P #39)
Patients want to know about the benefits and harms	Should be informed of both benefits and harms	"I would want to know [the pros and the cons]." (P #28) "I think [the doctor] should say [the benefits and harms] truthfully." (P #12)
	Benefits of early detection	"You know, you're not looking at this correctly. What are the pros and cons of not getting screened?...I mean, my brother didn't find out that he had cancer until it was at third-stage cancer. Is it not better to get screened and be on top of your condition, whether you get scared with a false positive or not? I don't know." (P #11)
	False positives (leading to anxiety, invasive tests, complications)	"False positives show something in the lungs that, number one....scares the crap out of them. And I mean frankly, it's very disconcerting. And secondly, some of the people in the medical profession who are easily excitable have been known to do too many tests or too much without further thought first." (P #13)
	Overtreatment/overdiagnosis	"How would you know? You would go with whatever recommendation they did. And if it was something that was overdiagnosed, only [the doctor] would know it. But they wouldn't necessarily come back to you and tell you, well, we overdiagnosed you and you shouldn't have had that, but you had it anyway. I just, I don't know about overdiagnosis." (P #5)
	Timing of information (not too much at first)	"And I think too much information is worse than not enough. Because if you have it all thrown to you and then you've got to decide what am I gonna look at, what am I not gonna look at, the tendency is to stop. Not look at anything. And that would be worse." (P #9)
Physicians need to communicate effectively to patients	Bedside manner	"They need to learn to talk to patients like they're not an object." (P #14)
	Be straightforward	"I think they should just be upfront and straight out with it. Don't pussy foot around it. Just, you know, let them know and then give them a list of the options of where to go from there." (P #21)
	Limit medical jargon (i.e., "positive" or "overdiagnosis")	"I was just saying my experience is that sometimes doctors don't talk to patients in English. They talk to them in medicine." (P #13) "Some of the terminology is gonna throw your patient emotionally or mentally and they're gonna go off on a mental tangent that you don't want them to go off on." (P #11)
Decision aids are helpful and influential in decision-making	Wanting smoking to be normalized	"I don't think we need to be beat up any more about our choice of bad habits. We already know." (P #43)
	Walk through with patient (discussion important)	"I'd like to have a health care worker go over it with me. If I just sat down and read this, I'd have as many questions after as I did before I read it....So I think a health care worker would be really good to have along with you while you read this." (P #39)
	Patients can be educated and fully informed	"I have confidence in my doctor too, but if they had a teaching aid like this, I think it would be well worthwhile to give it to me and give me a chance to better understand what they are saying." (P #14)
	Pictures/pictogram help to explain risks and benefits	"It seems really iffy. It doesn't make me want to go out and go get one." (P #19)

(Continued)

Table 4. (Continued)

Theme	Subtheme	Representative Quotes (Participant #)
The discussion must be tailored to the patient	Shocked at low risk on calculator	<p>"It was good to see where your risk was for somebody that smoked almost 40 years. And just quit when I was 57. To know my risk was just 2.9% in the low-risk area. That makes me really happy." (P #5)</p> <p>"You know like we did that test thing and it showed a low risk. Even though I'm in a low risk I'm still—what would you say? Well, it sounds confusing. High risk 'cause I smoke....but like in my head now it's like, well, if I'm that low then I'm not too worried about being screened." (P #27)</p>
	Shocked at how little benefit for those who get screened (saves 3 more lives of 1,000)	"I was rather surprised that the number of people who were actually helped by scans was so low." (P #13)
	Shocked at number of false positives	"I'm really surprised at the number. I mean more than a third of those tested come up with a false positive.... That doesn't seem like a very good test." (P #28)
	Format matters (pamphlet, web, video)	<p>"When I encountered that monster [computer] across the hall, I felt that I was being double crossed....I don't want to go to computer school, yours or anybody else's when I'm 74 years old. I resisted even getting a computer up until this time." (P #18)</p> <p>"I liked the web because you can direct yourself. The resources are infinite....But I understand for those who aren't savvy it would be very overwhelming." (P #16)</p>
	Leads to change in decision-making	<p>"I tell you what, it brings up questions. It questions my mind and makes me question—it'll make me ask questions for sure." (P #25)</p> <p>"But now I'm thinking, I'm not sure I'd take it [CT scan] at all." (P #28)</p>
	Every patient is different, some patients want more information	<p>"By now the doctor should know his patient well enough. What type of information can this patient handle? How fast, in what language? Not that the doctor should be condescending, but be on a level that will be heard." (P #43)</p> <p>"Be forthright and upfront....don't sugarcoat it." (P #17)</p>
	Some patients want less information and more recommendations from their doctor	<p>"I've reached the stage now I'll take the doctor's opinion and whatever he wants to do." (P #12)</p> <p>"I think too much information is worse than not enough." (P #9)</p>
	Patients have different preferences for decision-making roles	<p>"I have to know something. I have to be educated on this [in order to make a choice]." (P #26)</p> <p>"If my doctor told me to do it, I'd do it." (P #14)</p>
	Tailor the discussion to the individual	<p>"When it comes to the doctor, he needs to know his patient. You have to handle it differently with somebody taking antidepressants than somebody who's not." (P #15)</p> <p>"What [my doctor] did for the last person...he can't just do that for [me]." (P #4)</p>
	Cultural sensitivity	"It depends on the patient. Certain patients, I mean Seattle's a very diverse and cultural city. Each culture handles things differently. You know some people want to have their family involved in something like that. Some people don't. But it depends on the person." (P #15)

Definition of abbreviations: CT = computed tomography; P = participant.

none had undergone an LDCT for lung cancer screening and they initially knew little about lung cancer screening. In fact, 48% initially believed that there were no harms. After reviewing two different decision aids, web-based and paper, and participating in an active discussion on the topic, participants could identify false

positives, extra testing, and complications resulting from additional procedures as harms associated with screening. However, more than one-half believed that screening lowered the chance of getting lung cancer after conclusion of the focus groups. Whether this was due to poor understanding of the purpose of screening

or confusion regarding the meaning of the question is uncertain from our data.

Focus group discussion elicited many informative opinions regarding content, timing, and approach for communicating about lung cancer screening. Participants wanted straightforward information in simple language, with most preferring to

Table 5. Potential strategies and challenges to implementation

Consideration	Representative Quotes (Participant #)
Format and use	<ul style="list-style-type: none"> • <i>"Like I said earlier about prostate, colon, diabetes, it comes from your doctor. Just get a list of things you hear. Okay, you're old enough, you're getting to this age for this. We can check this, check this. Just put that on my list too. You know. Don't make anything different. Just add it to the list of things for me to get at a certain age with certain lifestyles."</i> (P #15) • <i>"If, when a doctor does say we want to do this, having a handout like this would really help. 'Cause all these things are going through your mind. You can take this home and read it when you regroup."</i> (P #8) • <i>"This [paper decision aid] would be a good thing for the doctor to hand to the patient in the office so that they can read it."</i> (P #8) • <i>"I think they should put it [paper decision aid] out on a table like magazines....By the time you get in there with your doctor you already have the questions you want answered."</i> (P #38) • <i>Would think more highly of your doctor if he or she used one of these tools [decision aids]: "Because I would think he's truly trying to get me to understand the severity and the ups and downs and the whatnots of the disease which is happening to me. So I would feel very appreciative."</i> (P #25)
Timing	<ul style="list-style-type: none"> • <i>"It would be a good idea for the doctor to explain everything to you. But something—not necessarily this [decision aid], but something like this that's very informative. He should have these handy in his office and give you one of them and tell you to, you know, sit down and study and read it. Before you make your decision."</i> (P #25) • <i>"Some doctors don't have the time to take you through stuff, much less the nurses. Because everybody's running crazy with patients and stuff. So it would be helpful if everything was on paper and then we finished the survey if we had concerns, bring that concern, make an appointment with the doctor and show him what you compiled in your rating. And then let's talk about it."</i> (P #5) • <i>"I would like a formal way of explaining things...from doctors. Like set aside a time, you know. Hands on. One on one. Where you know undivided attention is there."</i> (P #1) • <i>"Well, it depends on how much time they have, I mean, you know, being a doctor today you're lucky if you get time to sit down."</i> (P #13) • <i>"...Sending it home with the patient would be the most appropriate thing. Because in today's rush, rush, rush medical system, you know doctors don't just have the time to go over things step by step when they can send this home and let you come back and have your questions ready for them."</i> (P #21)
Who should deliver?	<ul style="list-style-type: none"> • <i>"I think the doctor should walk you through it. Your primary should walk you through it first. And then if he feels you need a specialist, then the specialist can turn around and walk you through it again."</i> (P #3) • <i>"I got more faith in my nurse than my doctor. And I see her more frequent."</i> (P #4) • <i>"I think [my doctor] should say it truthfully. Not just because it's a doctor and he wants to give—sometimes you can get a better rundown on that from a nurse practitioner than from a doctor....Because I suppose a nurse practitioner spends more time and studies in depth."</i> (P #12) • <i>"On a return visit you could have like a counselor who specializes in this....And they sit down, 'cause your doctor referred you to them."</i> (P #15) • <i>"I'd rather hear it from a person that has been through it. From a person that had to go through this."</i> (P #30) • <i>"Some of us are less intimidated by a nurse practitioner than a doctor."</i> (P #43)

Definition of abbreviation: P = participant.

know the full spectrum of harms and benefits before undergoing screening. Participants also wanted individualized information. Most participants preferred a paper decision aid, and many required assistance to use the computer and navigate online resources. Nonetheless, participants liked the additional information and risk calculator on the web-based decision aid.

Reviewing decision aids also informed participants' perceptions regarding the magnitude of lung cancer screening harms and benefits, particularly the online personal risk calculator and pictogram depicting the likelihood of different outcomes of screening. Although our study was not a trial comparing two decision aid formats or testing these decision aids in practice, it can inform future implementation work. First, many

participants expressed surprise at the perceived low magnitude of their lung cancer risk, using the personal online calculator; found this information helpful; and like individualized information. Second, many participants expressed surprise at the low absolute magnitude of benefit of screening and the large number of false positives. Finally, although the proportion was low, some patients thought that they would continue to smoke without worrying, if they had a normal LDCT scan. Further study is needed to understand how these perceptions influence smoking behaviors and acceptance and adherence to screening.

Strengths and Limitations

This study has several limitations. Focus group participants were from a single county hospital, potentially reducing

generalizability. No participants had personally experienced lung cancer screening although the majority had had a prior chest CT scan, and only 44% of participants met the U.S. Preventive Services Task Force eligibility criteria for lung cancer screening. Nonetheless, comparison of survey responses and results of focus groups indicates that attitudes and knowledge were similar between participants who met these eligibility criteria compared with those who did not, although our sample size overall was relatively small for quantitative analyses. Focus groups may encourage socially desirable responses more than individual interviews. Group cohesiveness and conversational momentum might have silenced dissenters. However, the facilitator sought input from all participants during the

discussion. Finally, although dominant themes were reviewed and confirmed by the facilitator and additional physicians absent from the focus groups, it is possible that different investigators could examine our data and identify different themes.

Our study has important strengths. We are among the first to review two types of lung cancer screening decision aids with a vulnerable patient population. We offer insights into the implementation of lung cancer screening in high-risk populations including diverse racial groups and low-income populations that may have

decreased access to screening, but can benefit significantly from screening (17, 18). The consistency of data across six focus group discussions, supplemented with quantitative survey data, suggests that the lessons learned are valuable and reproducible in this population.

Conclusions

In conclusion, engaging patients in shared decision-making, including talking about harms, benefits, and results of lung cancer screening, is difficult under ideal circumstances and is limited by appointment time constraints, translating

medical jargon to understandable terminology, and other barriers (13, 19–21). Discussing lung cancer screening within a vulnerable patient population may be uniquely challenging, but the participants in our study generally increased their understanding of harms and benefits after reviewing decision aids and discussing screening. Our findings can inform further work in the implementation of lung cancer screening among similar populations. ■

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References

- Aberle DR, Adams AM, Berg CD, Black WC, Clapp JD, Fagerstrom RM, Gareen IF, Gatsonis C, Marcus PM, Sicks JD; National Lung Screening Trial Research Team. Reduced lung-cancer mortality with low-dose computed tomographic screening. *N Engl J Med* 2011;365:395–409.
- Moyer VA; U.S. Preventive Services Task Force. Screening for lung cancer: U.S. Preventive Services Task Force recommendation statement. *Ann Intern Med* 2014;160:330–338.
- Tanoue LT, Tanner NT, Gould MK, Silvestri GA. Lung cancer screening. *Am J Respir Crit Care Med* 2015;191:19–33.
- Kinsinger LS, Atkins D, Provenzale D, Anderson C, Petzel R. Implementation of a new screening recommendation in health care: the Veterans Health Administration's approach to lung cancer screening. *Ann Intern Med* 2014;161:597–598.
- Wender R, Fonhtam ET, Barrera E Jr, Colditz GA, Church TR, Ettinger DS, Etzioni R, Flowers CR, Gazelle GS, Kelsey DK, et al. American Cancer Society lung cancer screening guidelines. *CA Cancer J Clin* 2013;63:107–117.
- Wiener RS, Gould MK, Arenberg DA, Au DH, Fennig K, Lamb CR, Mazzone PJ, Midthun DE, Napoli M, Ost DE, et al.; ATS/ACCP Committee on Low-Dose CT Lung Cancer Screening in Clinical Practice. An official American Thoracic Society/American College of Chest Physicians policy statement: implementation of low-dose computed tomography lung cancer screening programs in clinical practice. *Am J Respir Crit Care Med* 2015;192:881–891.
- Centers for Medicare & Medicaid Services. Decision memo for screening for lung cancer with low dose computed tomography (LDCT) (CAG-00439N) [cited 2016 March 30]. Available from: <https://www.cms.gov/medicare-coverage-database/details/nca-decision-memo.aspx?NCAId=274>
- Aberle DR, Adams AM, Berg CD, Clapp JD, Clingan KL, Gareen IF, Lynch DA, Marcus PM, Pinsky PF; National Lung Screening Trial Research Team. Baseline characteristics of participants in the randomized National Lung Screening Trial. *J Natl Cancer Inst* 2010;102:1771–1779.
- Volk RJ, Linder SK, Leal VB, Rabin V, Cinciripini PM, Kamath GR, Munden RF, Bevers TB. Feasibility of a patient decision aid about lung cancer screening with low-dose computed tomography. *Prev Med* 2014;62:60–63.
- Lau YK, Caverly TJ, Cao P, Cherng ST, West M, Gaber C, Arenberg D, Meza R. Evaluation of a personalized, web-based decision aid for lung cancer screening. *Am J Prev Med* 2015;49:e125–e129.
- Lau YK, Caverly TJ, Cherng ST, Cao P, West M, Arenberg D, Meza R. Development and validation of a personalized, web-based decision aid for lung cancer screening using mixed methods: a study protocol. *JMIR Res Protoc* 2014;3:e78.
- Fraenkel L, Peters E, Tyra S, Oelberg D. Shared medical decision making in lung cancer screening: experienced versus descriptive risk formats. *Medical Decis Making* 2016;36:518–525.
- Quaife SL, Marlow LA, McEwen A, Janes SM, Wardle J. Attitudes towards lung cancer screening in socioeconomically deprived and heavy smoking communities: informing screening communication. *Health Expect* (In press)
- Haiman CA, Stram DO, Wilkens LR, Pike MC, Kolonel LN, Henderson BE, Le Marchand L. Ethnic and racial differences in the smoking-related risk of lung cancer. *N Engl J Med* 2006;354:333–342.
- Jamal A, Homa DM, O'Connor E, Babb SD, Caraballo RS, Singh T, Hu SS, King BA. Current cigarette smoking among adults: United States, 2005–2014. *MMWR Morb Mortal Wkly Rep* 2015;64:1233–1240.
- Borkan J. Immersion/crystallization. In: Crabtree BF, Miller WL, editors. *Doing qualitative research*, 2nd ed. Thousand Oaks, CA: Sage Publications; 1999. pp. 179–184.
- Jonnalagadda S, Bergamo C, Lin JJ, Lurslurchachai L, Diefenbach M, Smith C, Nelson JE, Wisnivesky JP. Beliefs and attitudes about lung cancer screening among smokers. *Lung Cancer* 2012;77:526–531.
- Tanner NT, Gebregziabher M, Hughes Halbert C, Payne E, Egede LE, Silvestri GA. Racial differences in outcomes within the National Lung Screening Trial: implications for widespread implementation. *Am J Respir Crit Care Med* 2015;192:200–208.
- Wiener RS, Gould MK, Woloshin S, Schwartz LM, Clark JA. What do you mean, a spot? A qualitative analysis of patients' reactions to discussions with their physicians about pulmonary nodules. *Chest* 2013;143:672–677.
- Sullivan DR, Golden SE, Ganzini L, Hansen L, Slatore CG. "I still don't know diddly": a longitudinal qualitative study of patients' knowledge and distress while undergoing evaluation of incidental pulmonary nodules. *NPJ Prim Care Respir Med* 2015;25:15028.
- Slatore CG, Golden SE, Ganzini L, Wiener RS, Au DH. Distress and patient-centered communication among veterans with incidental (not screen-detected) pulmonary nodules: a cohort study. *Ann Am Thorac Soc* 2015;12:184–192.