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Qualitative Research

A qualitative study exploring why individuals opt out of lung cancer screening

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Abstract

Background. Lung cancer screening with annual low-dose computed tomography is relatively new for long-term smokers in the USA supported by a US Preventive Services Task Force Grade B recommendation. As screening programs are more widely implemented nationally and providers engage patients about lung cancer screening, it is critical to understand behaviour among high-risk smokers who opt out to improve shared decision-making processes for lung cancer screening.
Objective. The purpose of this study was to explore the reasons for screening-eligible patients' decisions to opt out of screening after receiving a provider recommendation.
Methods. Semi-structured qualitative telephone interviews were performed with 18 participants who met lung cancer screening criteria for age, smoking and pack-year history in Washington State from November 2015 to January 2016. Two researchers with cancer screening and qualitative methodology expertise conducted data analysis using thematic content analytic procedures from audio-recorded interviews.
Results. Five primary themes emerged for reasons of opting out of lung cancer screening: (i) Knowledge Avoidance; (ii) Perceived Low Value; (iii) False-Positive Worry; (iv) Practical Barriers; and (v) Patient Misunderstanding.
Conclusion. The participants in our study provided insight into why some patients make the decision to opt out of low-dose computed tomography screening, which provides knowledge that can inform intervention development to enhance shared decision-making processes between long-term smokers and their providers and decrease decisional conflict about screening.

Key words: Decision making and qualitative research, cancer screening, lung cancer, patients, primary health care.

Introduction

Lung cancer screening with low-dose computed tomography (LDCT) has become increasingly available in the USA since its Grade B recommendation from the US Preventive Services Task Force (USPSTF) in 2013 for long-term smokers (1). Health care systems have been rapidly rolling out screening programs (2). For the first time, shared decision-making has been tied to cancer screening through reimbursement mandate of documentation of a shared decision-making and counselling visit for reimbursement of lung cancer screening (3). This Medicare coverage requirement is due to be implemented in January 2017 (2,3). Shared decision-making is conceptualized as a process in which a health care provider offers information about a treatment or health care option to an individual, discussing the benefits and potential harms as well as uncertainties, and engaging the patient to weigh their values and preferences to arrive at a decision collaboratively (4).

For eligible patients, the decision to participate in screening may not be straightforward. Lung cancer screening is new, and many individuals are unaware of the test and its balance of benefits and risks. While the primary benefit of lung cancer screening is the potential to find lung cancer at an earlier stage where more treatment options exist, the risks associated with lung cancer screening include the potential for overdiagnosis, cumulative radiation exposure with a yearly commitment to screen with LDCT and false-positive findings. An indeterminate finding such as a lung nodule can lead to subsequent invasive follow-up procedures including a biopsy (5,6). Furthermore, lung cancer screening targets long-term smokers. Unlike the relatively healthy populations targeted for breast and colorectal cancer screening, this population is unique, different and has a high potential for smoking-related comorbidities. Of equal importance, smokers experience stigma, perceive blame and battle nicotine addiction. Perceived self-infliction secondary to the choice to smoke presents a layer of complexity not present in other types of cancer screening. Based on previous qualitative work, stigma and medical mistrust seem to be uniquely relevant in lung cancer screening (7). Because stigma and medical mistrust may influence the decision not to screen for lung cancer, understanding the decision-making process among patients who opt out is critical. This knowledge is a foundational component of understanding the patient perspective and can inform effective intervention development to enhance the shared decision-making process. The purpose of this study was to explore the patient decision to opt out of screening after receiving a provider recommendation for lung cancer screening. There is a dearth of literature on the patient perspective of lung cancer screening (7–9), and to our knowledge, no one has explored the patient decision to opt out of screening after having a discussion about screening with a provider and receiving a recommendation. Findings from this study extend the work done by others exploring the decision to screen by offering insight into the decision not to screen (9–11), which can inform interventions that target both the patient and provider to enhance the shared decision-making process in lung cancer screening decisions.

Methods

Design overview and setting

We conducted a qualitative study to explore descriptions of life events shared by people with a common concern (12); in this case, the decision to screen for lung cancer. In 2015, Group Health Cooperative (GHC), a mixed-model delivery system in Washington state, had a soft launch of a population-based lung cancer screening program, set within primary care clinics. Information regarding the new screening guideline was actively disseminated to providers and a registry for providers to document lung cancer screening discussions employed. The soft launch did not involve active outreach to screening-eligible patients meaning patients who met screening guidelines did not receive promotional materials outside of a clinic visit about lung cancer screening. Patients were identified in the context of a health care appointment with their primary care provider in which a discussion about lung cancer screening occurred. For providers, the screening guideline was deployed through lunch-time continuing medical education and direct communication through electronic clinical pearls and a toolkit within the electronic health record system to support documentation of a patient discussion and the patient's decision about screening. At the initial program launch, there were no formal shared decision-making tools provided, but soft decision aides for provider use and an After Visit Summary were available. These did not meet formal decision aid criteria (13). GHC has since updated their decision-making tools to exceed those criteria.

Medical assistants updated smoking history and pack-year information when patients arrived for a health care visit to identify potentially eligible patients for the health care provider. The electronic health record was modified with a module designed and developed within GHC to systematically capture information about individuals approached for lung cancer screening including eligibility and documentation about the patient's decision whether or not to screen. In addition to knowing if screening was discussed, we were able to identify individuals who opted out of screening.

Recruitment of participants

We recruited 18 participants aged 55–77 years using a purposive sampling strategy from GHC between November 2015 and January 2016 who met the following inclusion criteria: (i) eligible for and offered lung cancer screening by their primary care provider in the past 4 months prior to recruitment; (ii) did not have lung cancer screening despite being offered referral; (ii) able to speak and understand English; and (iv) able to participate in a telephone interview. Individuals eligible for lung cancer screening according to the USPSTF guideline are aged 55–77 years old, current or former smokers who have quit within the past 15 years and have 30 pack-year tobacco smoking history.

We used electronic health records to identify potential participants to whom recruitment letters, signed by the co-principal investigators, were sent. The recruitment letter introduced the study opportunity, indicated they would be called by study staff and offered the research office's telephone number to call and leave a message to opt out of being contacted. One week after recruitment letters were mailed, study staff followed up by telephone with individuals who did not call to refuse participation. Ninety-four recruitment letters were mailed; four individuals called and left a message to opt out of further contact about the study. Seventy-four participants were reached by telephone. All were screened for eligibility before being offered participation in the study. Of the 74 reached and screened, 36 were eligible, 17 declined to participate in the study and 19 participated (52.8%). Socio-demographic variables did not differ between those who did and those who did not agree to participate. Once an individual was determined to be eligible and willing, the informed consent process was performed. Most interviews took place during the same outreach call. However, some interviews were scheduled at a later time that was more convenient for the participant. Participant recruitment ended when sufficient information had been obtained to identify several distinct themes and saturation was reached (14). A $50 check was provided after completion of the interview for their time.

Data collection

We developed an interview guide that focused on (i) details about the lung cancer screening conversation with the provider and perceptions of the patient–provider discussion about screening and (ii) reasons for opting out of lung cancer screening including specific factors influencing the patients' decision. A trained research specialist conducted individual telephone interviews using this semi-structured interview guide (Table 1). Interviews were digitally audiotaped, transcribed verbatim and de-identified by a secure transcription service. Participants were also invited to ask questions and provide additional details/feedback. Interviews ranged from 36 to 68 minutes in duration. Data collection ended after 18

Table 1. Sample items from the semi-structured interview guide

Can you please describe how your provider told you about lung cancer screening?
How did she/he describe why lung cancer screening was important and what it involves?
When your health care provider recommended lung cancer screening to you, what was your response?
  Why do you think you responded that way?
Was it difficult or easy for you to make your decision about lung cancer screening?
  Can you please explain why?
Why do you think your provider recommended that you consider having lung cancer screening?
Does anything worry you about lung cancer screening that you have not mentioned?

Data collected at Group Health in Seattle, WA (November 2015–January 2016).

interviews because, although the details and examples were often unique, saturation was reached in which information to identify distinct themes relevant to the decision to opt out of lung cancer screening was obtained.

Data analysis

Data were analyzed using standard content analytic procedures (15). Two researchers with expertise in cancer screening and qualitative methods (LCH and SDB) conducted data analysis by independently reading all transcripts. A coding scheme was developed, with input from the research team comprised of researchers with expertise in lung cancer screening behaviour, cancer epidemiology and health services research. Each transcript was independently coded by providing labels for each relevant text unit, which is any word, phrase, sentence or story that provided information to address the study purpose. An approach using inductive analysis was used to derive themes from the iterative review and interpretation of the data (16). A coding matrix was created using a Microsoft Word table format to display the relevant, identified text units. Text units were then compared, contrasted and independently grouped into subcategories. The researchers then met to discuss themes that emerged from individual coding and compare the degree of congruence between coding, themes and classifications. Discrepancies were discussed and reconciled by consensus.

Ethical considerations

The study was approved by the Group Health Research Institute's Human Subjects Research Committee for all study activities prior to the initiation of recruitment. Participants provided verbal consent prior to data collection. Confidentiality was assured by de-identification of transcripts using identification codes.

Results

The median (interquartile range) participant age was 68 (57, 74) years. Most were Caucasian (89%), female (61%) and current smokers (61%) (see Table 2). Participants recruited into and completing the study represented health care encounters of 10 unique primary care providers. Results are organized according to two main topics: (i) patient–provider discussion about lung cancer screening and (ii) reasons for opting out of lung cancer screening. Table 3 summarizes themes and subthemes of the findings.

Table 2. Participant socio-demographic characteristics, Group Health Cooperative, Seattle, WA, November 2015–January 2016

Variable	*N*
Gender	
Male	7
Female	11
Race	
White	16
Black or multiracial	2
Smoking status	
Current smoker	11
Former smoker	7
	Median (IQR)
Age (years)	68 (55, 74)

IQR, interquartile range.

Patient–provider discussion about lung cancer screening

All participants reported the provider initiated the discussion about lung cancer screening opportunistically, meaning that the patients were having either general wellness visits (12 visits) or were being seen for a particular condition or symptom (6 visits). The majority had never heard of lung cancer screening before this discussion, and most described the discussion as short or limited, regardless of type of visit. Participants reported screening being brought up in the context of their smoking history, either because they were current smokers or had been a long-term smoker. Illustrative comments include 'We talked about cigarette smoking [as] something that I knew was going to greatly impact diabetes, but at that point my plate was really full, and we could go into the smoking at a later date…he suggested at that point that maybe I should get the lung screening while I was getting everything else tested' (F, age 66); 'He told me that I would be a very good candidate for it and that he recommends it highly' (M, age 70); and 'She said very specifically because I'd smoked more than 15 years…she said it was a particular x-ray for smokers' (F, age 69).

Participants consistently described brief discussions presenting the option of lung cancer screening but, from their perspective, lacked description or engagement in a shared discussion about screening beyond eligibility. Two themes emerged: (i) Being Qualified to Screen and (ii) Discussion Followed by Provider Recommendation.

Being Qualified to Screen was characterized by a brief presentation of lung cancer screening as an option that primarily centred on screening qualification secondary to smoking history followed by printed materials to take home. Screening was presented as an option and not typically accompanied by a specific recommendation. Many participants noted the discussion was quite brief and a small component of the visit. Most information was gleaned from the educational printed materials provided and not the patient–provider discussion. These types of experiences are illustrated in the following quotes: 'She [provider] handed me a paper and she said 'read over this'…she didn't really [describe it]. I got most of my information off the paper. I mean, she said I didn't have to do it, but if I'd like to, they could set it up and I could go on and have it done' (F, age 63); 'She [provider] had just brought it up and said 'oh, here's some paperwork and if you want to do this, you can' (F, age 69); and 'She gave me a printout and I brought that home and read it, mostly. That's where I got most of the information' (F, age 67).

Discussion Followed by Provider Recommendation was characterized by a short provider-initiated and led discussion followed by a screening recommendation. For example, one participant noted, 'I

Table 3. Major study themes and subthemes

Objective	Theme	Subtheme	Example quote
Patient–provider discussion about lung cancer screening	Being Qualified to Screen		'She [provider] handed me a paper and she said 'read over this'… she didn't really [describe it]. I got most of my information off the paper. I mean, she said I didn't have to do it, but if I'd like to, they could set it up and I could go on and have it done'.
	Discussion Followed by Provider Recommendation		'He recommended it because I had smoked a certain amount of time, a certain amount of cigarettes per day and…was eligible'.
Reasons for opting out of lung cancer screening	Knowledge Avoidance	Fear of the Disease	'so I didn't choose to go do the test. If I did try to go do the test, I would be kind of scared, because I've been smoking since I was 12 and I really don't—I mean, I can imagine what my lungs look like and what they might find'.
		Fear of the Treatment	'I think it's fear of the unknown—if I know, well then there's a scary response. You know you have to follow through and do more and more'.
	Perceived Low Value	Wasted Effort	'It could show me if I had lung cancer and—what are they going to do?…screening for it doesn't really make any difference because I'll either come down with lung cancer or I won't'.
		Scepticism	'What is it going to do? What is it going to prove? That I don't have it right now. But in five years I could end up developing lung cancer from my past exposure'.
	False-Positive Worry		'I did schedule one and then after I read the print out and the office called me, I cancelled it…the false positives were so high'.
	Practical Barriers		'…I was still working at that time and I really didn't have time to get over there during the week and so I haven't had it done'.
	Patient Misunderstanding		'once we got to the point where I realized it wasn't going to be covered by my insurance, that was basically the end of it…if it had been less expensive, I would have done it'.

know she said that she wanted me to have it done, because I'd smoked before, and at my age it should be done', and another describing, 'he recommended it because I had smoked a certain amount of time, a certain amount of cigarettes per day and…was eligible' (M, age 72).

Reasons for opting out of lung cancer screening

When asked about the decision to opt out of lung cancer screening, the majority indicated they did not opt out initially during the clinical encounter, but rather their decision to opt out was made after they left the office. Five primary themes emerged: (i) Knowledge Avoidance; (ii) Perceived Low Value; (iii) False-Positive Worry; (iv) Practical Barriers; and (v) Patient Misunderstanding. All five themes are reflective of barriers, which is theoretically consistent with the Health Belief Model (17).

Knowledge Avoidance primarily manifested as fear of finding lung cancer and what that would mean for the individual. Subthemes reflective of Knowledge Avoidance included (i) Fear of the Disease and (ii) Fear of the Treatment. A male participant described, 'I'm 61 years old. I mean, you know, if I have lung cancer…basically I just don't want to know about it', highlighting his fear of the disease. Similarly, a 66-year-old woman stated, 'so I didn't choose to go do the test. If I did try to go do the test, I would be kind of scared, because I've been smoking since I was 12 and I really don't—I mean, I can imagine what my lungs look like and what they might find'. Whereas a 59-year-old woman recounted her decision to opt out of lung cancer screening by noting, 'I think it's fear of the unknown—if I know, well then there's a scary response. You know you have to follow through and do more and more'.

Perceived Low Value was characterized as feeling the screening test is of little to no benefit. Subthemes reflective of Perceived Low Value included (i) Wasted Effort and (ii) Scepticism. There was a disconnect between the benefit of potentially finding lung cancer early and what could be done if lung cancer was detected. Reflective of the subtheme, Wasted Effort, a 61-year-old man noted, 'It could show me if I had lung cancer and—what are they going to do?...screening for it doesn't really make any difference because I'll either come down with lung cancer or I won't'. Scepticism was also voiced about the benefit of a negative screening result. For example, a 63-year-old woman adamantly noted, 'What is it going to do? What is it going to prove? That I don't have it right now. But in five years I could end up developing lung cancer from my past exposure'.

False-Positive Worry was a concern raised by five participants. They indicated they were heavily influenced not to screen after reading the take-home materials that described the likelihood of a false-positive result that could lead to invasive procedures. Having a false-positive would induce too much stress and anxiety and caused them to distrust the tests' value. Illustrative comments include a 66-year-old female noting, 'It was saying 'risks of screening, false positive test results'…I had just gotten an abnormal mammogram reading…and I'm sitting here looking at a 95% chance that I'm going to be misdiagnosed, and I have to go through it all again. Only this time the tests involved are more invasive. That didn't exactly excite me…I just was not ready to put myself through that kind of stress'. Similarly, another participant recalled, 'I did schedule one and then after I read the print out and the office called me, I canceled it… the false positives were so high. I thought why—I wanted to think about it some more, because I thought that would be so stressful to think that you had it, and really you didn't. I mean it was like 90-some percent, I believe' (F, age 67).

Practical Barriers represented time and logistical issues. Some opted out because of the inconvenience associated with the screening location and time it would take to travel to and from the facility to have the scan. For example, one participant noted, 'She [provider] had it all set up—I just had to give them a day I'd come in and see them, but I was still working at that time and I really didn't have time to get over there during the week and so I haven't had it done' (M, age 68).

Finally, a theme characterized by Patient Misunderstanding emerged as well. Even though lung cancer screening is a covered preventive service with a zero-dollar copay under the Affordable Care Act (3), some misunderstood associated screening costs as noted by a 65-year-old woman noting lung cancer screening was 'just very, very expensive…it was like $500. I gathered that was per year. It just seemed more than I wanted to spend', and another participant stating, 'once we got to the point where I realized it wasn't going to be covered by my insurance, that was basically the end of it…if it had been less expensive, I would have done it' (M, age 67). Ultimately, these participants made the decision to opt out of lung cancer screening secondary to misunderstanding associated out-of-pocket cost.

Discussion

To our knowledge, this is the first study to explore the decision to opt out of lung cancer screening in screening eligible patients. Reasons individuals identified for opting out of screening were reflective of barriers consistent with the Health Belief Model (17). As established in breast and colorectal cancer screening (18,19), and early qualitative research in lung cancer screening (7,9,20–22), fear of finding and being diagnosed with cancer is a compelling reason to decline to screen. Feeling screening tests are a waste of time or unnecessary, as well as practical reasons such as time, inconvenience and cost are consistent with reasons given by individuals who opt out of other types of cancer screening (18,19). Based on the educational materials, many participants expressed concern about the high number of false-positive findings and the worry that would induce along with the potential for subsequent invasive diagnostic procedures. Unlike other types of cancer screening, this highlights potential messaging and presentation differences in lung cancer screening patient educational materials versus other types of cancer screening worthy of further exploration. Additionally, many patients reported the lung cancer screening topic as a small component of their health care encounter and being provided post-visit educational materials to review leaving the patient to process themselves.

Knowledge regarding lung cancer screening overall as well as benefits and potential harms remains low in the general US population (7,9). When a patient comes in for a clinical visit having never heard of lung cancer screening, the expectation of making an informed decision is a challenge. For those in this study, because most were unaware of lung cancer screening, screening being described and offered in the context of a brief discussion or via pamphlet did not foster engagement to fully consider the benefits versus risks nor result in an informed decision. Further, for those patients in the study that described receiving patient education material and making the decision to not screen for lung cancer based upon the high false-positive rate associated with screening, this highlights the complexity of educating patients about cancer screening in general. A false-positive rate is the rate of positive results that are identified and subsequently determined to be benign representing the sensitivity of the test versus the specificity (23). While it is accurate to present a 95% false-positive rate in lung cancer screening and a recommended talking point for providers in patient education regarding screening driven by the USPSTF lung cancer screening guidelines (3), it is understandable that patients struggle to interpret this information accurately. This highlights the complexity of presenting lung cancer screening to a patient outside of a clinical encounter reflective of shared decision-making or through a pamphlet and expecting the patient to make a high-quality, informed decision. Shared decision-making is a process that may necessitate more than one clinical encounter and/or pre- and post-visit support to foster an informed, values-based decision. Tailored lung cancer screening materials sent to an eligible patient pre-visit may help prime the patient for the shared decision-making process about screening allotting more time for providers to focus on educating patients about their personal risk and complex concepts related to cancer screening such as false-positive results and potential for overdiagnosis. Furthermore, the post-visit time period is ideal for continued educational support for those who are undecided after engaging in a patient–provider discussion about lung cancer screening (24–26). It is important, however, to remember that within the context of opportunistic screening discussions, there might not be sufficient time to fully discuss all screening-related questions as well as the actual intent of the visit. Therefore, it is essential for practices to consider how to share material with patients pre- and post-visit to address time constraints while engaging and empowering patients in the decision-making process.

Our findings provide an initial glimpse into the decision-making process about lung cancer screening early in its implementation post-USPSTF recommendation. The timeline for guideline diffusion into practice for both patients and providers is critical as we assess lung cancer screening implementation over time. With the reimbursement requirement of shared decision-making (2), we have a unique opportunity to design health care encounters that promote an informed, values-based decision around screening. Patients who are involved in decision-making about their health report increased decision quality (27). Specifically, decision quality can be improved through (i) increased knowledge; (ii) supporting a patient's values; (iii) increasing patient–provider communication, including the provision of information people understand consistent with educational level; (iv) helping patients who are undecided make a decision that is right for them; (v) decreasing decisional conflict through meaningful shared decision-making interactions; and (vi) decreasing passive participation in the decision-making process (28,29).

Limitations and strengths

The results of this study should be interpreted in the context of its limitations and strengths. While a key ingredient in qualitative research is development of rapport during interviews, performing a telephone interview to collect data may influence rapport, which may limit the depth of the interview and impact the findings. However, it has been noted that in the case of sensitive information, a telephone interview may foster individuals to feel comfortable and thus able to disclose sensitive information (30), which we found to be the case with exploring the decision to opt out of a screening recommendation with our sample. In addition, participants were recruited within 4 months of their health care visit in which lung cancer screening was discussed, offered and declined by the individual. Although the participants in our study did not have difficulty recounting their perspectives on reasons for declining to undergo lung cancer screening, there was a potential for recall bias. Finally, participants were limited in racially/ethnically diverse representation potentially influencing the results. Future studies exploring the decision to opt out of lung cancer screening should include increased numbers of individuals from diverse backgrounds to provide a more robust picture of the opt out decision. A strength of the study was the ability to identify patients who were offered lung cancer screening by their provider. In many systems, it is difficult to evaluate individuals who opt out of a recommended service, as systematic documentation of the service being offered and declined is not captured.

Conclusions

Results from this study indicate that lung cancer screening awareness is low among screening-eligible individuals. Screening offers a clinical platform in which shared decision-making is ideal. While providers are shifting to shared decision-making in other types of cancer screening (29), with lung, patients and providers are new to both the screening option and the shared decision-making process adding layers of complexity to the implementation of lung cancer screening. Therefore, it is critically important that both patients and providers are supported in methods that foster a shared decision-making process.

Declaration

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Conflict of interest: none.

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