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Challenges to Educating Smokers About Lung Cancer Screening: a Qualitative Study of Decision Making Experiences in Primary Care

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Abstract

We sought to qualitatively explore how those at highest risk for lung cancer, current smokers, experienced, understood, and made decisions about participation in lung cancer screening (LCS) after being offered in the target setting for implementation, routine primary care visits. Thirty-seven current smokers were identified within 4 weeks of being offered LCS at seven sites participating in the Veterans Health Administration Clinical Demonstration Project and interviewed via telephone using semi-structured qualitative interviews. Transcripts were coded by two raters and analyzed thematically using iterative inductive content analysis. Five challenges to smokers' decision-making lead to overestimated benefits and minimized risks of LCS: fear of lung cancer fixated focus on inflated screening benefits; shame, regret, and low self-esteem stemming from continued smoking situated screening as less averse and more beneficial; screening was mistakenly believed to provide general evaluation of lungs and reassurance was sought about potential damage caused by smoking; decision-making was deferred to providers; and indifference about numerical educational information that was poorly understood. Biased understanding of risks and benefits was complicated by emotion-driven, uninformed decision-making. Emotional and cognitive biases may interfere with educating and supporting smokers' decision-making and may require interventions tailored for their unique needs.

Keywords Cancer screening · Decision making · Psychology · Smoking cessation · Qualitative research

Introduction

Annual lung cancer screening (LCS) is being widely implemented and has the potential to reduce the number of deaths due to the leading cause of cancer deaths by identify lung cancers at earlier stages [1, 2]. Despite this potential, endorsement by multiple professional groups, recommendation by the United States Preventive Services Task Force, and coverage under Medicare, uptake of LCS thus far has been low [3–7]. Poor understanding of LCS among eligible patients is thought to be one reason for low uptake, and a growing body of research on patient perspectives about LCS has found that many patients misunderstand important aspects of LCS, including the purpose of screening, eligibility criteria and status, and potential harms and benefits [8–11].

As a result of poor patient understanding, and concerns that screening will reinforce harmful beliefs that support continued smoking, shared decision-making visits and use of decision aids are required for reimbursement to educate eligible patients and promote informed and shared decision-making [5]. However, it is unclear how to counsel and educate current

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and former smokers effectively about LCS and its harms and benefits. Studies investigating the effects of decision aids have found only modest improvements in patients' knowledge or attitudes. Incorrect beliefs have been found to persist after patients receive decision aids, including that all current and former smokers should be screened for lung cancer, that ineligible patients would participate in screening if offered, and that null screening results mean that patients can continue smoking without worry of lung cancer [12–14]. Little research has investigated the effectiveness of shared decision-making visits in correcting misperceptions, but initial results are also unclear. For example, one recent study found that despite improving knowledge about LCS, only 66% of patients who received a shared decision correctly identified benefits of LCS immediately afterward, and 21% could not identify a single harm of LCS 1 month later [15].

LCS is unique among recommended cancer screening services in that eligibility requires a significant smoking history, and there is reason to suspect that cigarette smoking may be related to unique challenges to informed decision-making. Smoking has become increasingly concentrated among individuals of lower income and educational attainment, with psychiatric comorbidities, and with more chronic health conditions and greater overall illness, proxy indicators for sociodemographic factors of individuals who are generally more difficult to engage in their health care and are less activated regarding health care decisions [16–19]. Smoking behavior itself may create unique cognitive dissonance or biases that make informed decision-making more challenging [20]. Most people, including smokers, acknowledge that smoking poses serious health risks [21, 22], yet many smokers endorse systematic biases and misconceptions about the risks conferred by smoking, including mythic or distorted beliefs about harms caused by smoking and unrealistic optimism about their risk for lung cancer [21–24]. Current smokers may also experience strong emotions such as fear, shame, or regret related to ongoing smoking, particularly during LCS [9, 11, 25–29]. Psychological research indicates the profound influence emotions can have on patients' beliefs and decision-making, yet research investigating patients' decision-making about LCS has insufficiently incorporated affective factors [30, 31]. Moreover, the patient-centered research about LCS to date may have inadequately captured the potentially unique needs of smokers seen in clinical practice, as much of it has been conducted with broadly eligible patients, including many former smokers or ineligible smokers, or have recruited patients from screening trials or who were not actually offered screening in a clinical setting.

How current smokers actually decide whether to participate in LCS has not been fully investigated. We sought increase understanding of smokers' decision-making by qualitatively exploring how smokers who were offered LCS in the target setting for implementation, routine primary care visits, experienced, understood, and processed the information they received about harms and benefits and made decisions. Specifically, we aimed to identify current smokers' barriers to informed decision-making about LCS when it is offered during a routine primary care visit.

Methods

Study Design

In 2012, the Veterans Health Administration (VHA) launched an eight-site Lung Cancer Screening Clinical Demonstration Project (LCSCDP) to address key questions about the patient experience, outcomes, and resources necessary to develop a patient-centered, evidence-based LCS program [32, 33]. As part of LCSCDP, the VHA National Center for Health Promotion and Disease Prevention developed patient education materials for use by clinicians to help patients make informed decisions about whether to be screened. The main print patient education resource, "Screening for Lung Cancer," (Appendix 1) was designed to inform patients about the harms and benefits of LCS and encourage patients to consider their personal preferences and values relevant to screening [34].

Within this context, we conducted a supplementary study using semi-structured telephone interviews with patients from seven of the LCSCDP study sites that were actively conducting screening between May 29 and September 22, 2014 [34]. Potential participants were identified in the VHA's medical record system and mailed letters describing the study within 4 weeks of the first offer of screening, and those who returned signed informed consent forms by mail were interviewed by telephone; Veterans identified more than 4 weeks after being offered screening were not invited for participation because the intent of the study was to interview participants before and after they had been screened. All study procedures were reviewed and approved by the VA Puget Sound Health Care System Institutional Review Board and the University of Washington Institutional Review Board. Additional methodological details, as well as results describing attitudes and perceptions about smoking cessation, have been published previously [29].

Participants

Participants had to be currently smoking and meet VHA's general eligibility criteria for LCS, which included being between the ages of 55 and 74 years and having a smoking history of at least 30 pack-years. VHA enrollees are disproportionately white men, so women and nonwhite individuals were oversampled for contact to ensure their inclusion in the study [35].

Approach

Telephone interviews were conducted using a semi-structured interview guide (Appendix 2) that included questions and probes

regarding participants' experience being offered LCS and subsequent decision-making, the discussions they had with providers about LCS, and their understanding of the benefits and risks of LCS. Interviews were digitally recorded and transcribed by research staff (not involved in analysis) with notes by the interviewer about the conduct of the interview included for analysis.

Data analysis was conducted by an analytic team of two clinical psychologists (P.G., G.S.) using inductive content analysis (themes were derived from the data, rather than specified a priori) [36]. Analysis began with immersion in the data by reading interview transcripts and listening to audio recordings of interviews. Next, the analytic team assigned initial descriptive codes to summarize the content and meaning of segments of participants' responses. Codes were jointly reviewed and iteratively refined to resolve discrepancies and redundancy between coders. Finally, codes were combined and conceptually organized into themes related to how smokers processed and described their understanding of the harms and benefits of LCS and how they described this understanding influencing their decision about participating in LCS. Coding and theme generation were repeated in iterative cycles until a saturation point was reached in which no new codes were identified. Each theme was refined through discussion among the research team (which included a family medicine physician, a pulmonologist, psychologists, and health service researchers) and by verifying the trustworthiness of themes against the data to reach consensus [37–39]. Representative quotes for each theme were extracted for presentation as examples. ATLAS.ti (version 7.5.10) was used for data management and coding [40].

Results

Participants

Of the 186 patients invited to participate, 37 were recruited and interviewed. Participants who agreed to be interviewed were primarily (89%) men, with average age of 62 years (range, 55–72) and smoking histories of 49 pack-years. Overall, 27% were black or minority race or ethnicity (11% missing or declined to provide race/ethnicity). Most participants agreed to screening; only 11% of participants declined screening or had delayed scheduling their screening exam until data collection had ended.

Main Findings

Overall, participants appeared to poorly understand the benefits and risks of LCS. Most participants held very positive views of LCS and overwhelmingly regarded the perceived benefits of early detection as a compelling reason to participate in screening: "If it stops the cancer, stops it early in people that is what it is all about." Although all patients could identify potential benefits of LCS, very few, if any, potential harms were identified: "I thought it was a win-win situation. I didn't see no down side to it." A common sentiment among participants was "there's really no risks." Some harms, such as overdiagnosis, were not mentioned at all. The overestimation of benefits and minimization of potential harms was succinctly described by one participant: "the risks are very low and the benefits are astronomical." Very few participants expressed feeling uninformed or unable to identify their preferred choice or decide. However, while most acknowledged some consideration of benefits in their decision-making process, consideration of accurate factual or probabilistic health information was rare, particularly regarding potential harms of screening.

Barriers to Informed Decision-Making

Barriers to informed decision-making were categorized into five themes. We include selective quotes to illustrate themes in the text; additional quotes grouped by theme can be found in Appendix 3.

Fear of Lung Cancer

> "… I really am interested is because my best friend, we have been friends for 30 years, her youngest brother died, it will be a year in October and two years since he had … He was several years younger than me and when it strikes at home it's kind of scary so when this project came up I thought let's be a little proactive."

All participants appeared to be aware of lung cancer as a risk of smoking and many expressed fear of lung cancer. Fears of lung cancer were described as instrumental in participants' decision-making process. Participants regarded LCS positively because they believed in the potential benefits of early detection to address their fears. For several participants, fears were tied to personal experiences, such as a friend or family member who had died from lung cancer, or pulmonary symptoms (shortness of breath, needing to use inhalers, etc.). These fears appeared to outweigh and bias the information they received regarding the probability of potential harms and relatively unlikely benefits of LCS.

Shame, Self-Blame, and Futility

> "They all talk to me about smoking and I would give anything to quit. I have tried everything. I want to quit. I just got electronic cigarettes and I am going to try those… I've had serious scares in the past which should have done it but I am just stupid you know. I am just

> really stupid to keep smoking I just... always end up going back but I'm going to do it. I've got to."

Participants situated the decision to be screened within their shame, guilt, regret, or self-blame about their long smoking histories. Every participant reported having tried to quit smoking, and most reported continual failure: "I have done it all. You name it I have done it." The inability to continuously abstain from smoking prompted a strong sense of futility or fatalism regarding continued smoking, and these beliefs were influential in evaluating LCS favorably in their decision-making process. For instance, one participant saw lung cancer and continuing to smoke as inevitable and wanted LCS to improve his chance of surviving this inevitable cancer:

> "I am highly unlikely to quit smoking and it is probably going to kill me… the earlier it is caught the better your chance of surviving it. I have a sister with lung cancer so I am aware of that already. She was diagnosed about 2 years ago, so any opportunity that is early, she was diagnosed early and they have kept her alive so far. I am well aware that early detection increases the possibility of survival."

Describing long histories of smoking and multiple ineffective attempts to quit evoked strong expressions of negative self-judgment and guilt, including use of words such as "ugly," "stupid," "weak," "I am sorry," and "angry at myself." Shame associated with smoking was linked to these feelings, as one participant stated: "you hate to light up a cigarette because everybody looks at you. It is like shaming you."

Screening itself had a judgmental or punitive function for some participants; one described the offer of LCS as his opportunity to "face the music." Negative fatalistic attitudes about the inevitability of lung cancer or futility of quitting smoking caused many to fixate focus on early detection benefits of LCS and precluded a balanced and rational consideration of benefits with potential harms of LCS. Despite their fears about lung cancer, some participants expressed optimistic hope that early detection would benefit them personally by catching the lung cancer that they felt was inevitable: "I've been smoking since I was 13, so all those years I might have had a little bit more than COPD, but if I do hopefully I'll get it diagnosed and hopefully I can get it treated to when they caught it in time so that's the main benefit of this screening."

Perceived Ability of LCS to Quantify and Measure Risks and Harms

> "I've abused my body, and I've got beautiful grandchildren and I want to see them grow so I want to see what I have to do to maintain it…to see how much damage I've really done, and see if I can't repair it."

Patients consistently expressed beliefs that LCS would measure the damage smoking had caused to their lungs. They believed that screening would provide them with categorically clear, actionable information about their lungs (e.g., having lung cancer or not). For some participants, this seemed to stem from their understanding that CT scans are more detailed than X-rays, and that this added resolution would allow them to "see" the harms more clearly: "I have had occasional irregular chest X-rays in the past and have considered them an appropriate diagnosis tool to monitor what is probably inevitable in my lungs. And the CT seems to be from everything I have read about it sort of super more detailed X-ray so that's my reasoning." Satisfying curiosity about what LCS would measure, and "just wanting to know" were viewed as added benefits that increased their positive impression of LCS. The decision to participate in LCS was also framed as a means of informing some future health decisions, such as quitting smoking. However, participants did not mention considering the possibility that screening could provide vague or indeterminate evidence of harm, or that they might face future decisions about potentially harmful downstream procedures. The offer of LCS for some further reinforced their perception that smoking was mainly harming their lungs and that lung cancer was the primary smoking-related concern.

Deference to Providers

> "Basically my doctor has been badgering me for years to quit smoking. He heard of your lung screening test and basically thought I could benefit from being screened since I met your criteria. Since I'd like him to stop his badgering of me I did what he said. I know he is badgering me for my own good."

Smokers described ceding decision-making to their providers and reported respectfully yielded to the judgment or opinion of their physicians. Participants described positive, trusting relationships with their physicians and other primary care team members and described their providers having fundamental influences on their decision-making. Few participants explicitly recognized that with the offer of LCS was an opportunity for patient-centered shared decision-making. For example, some participants appeared unaware that they could decline their physicians' recommendation that they "should" participate in LCS.

Lack of Interest and Understanding of Numerical Risk Information

> I didn't understand too much of it [numeric information]… I didn't really investigate it that much to be honest with you. I mean I just took the test, I didn't

really worry about the brochure, because what good is a brochure to me, I don't know how this thing is going to come out. Is that bad?"

Although most held favorable impressions about the print educational materials given as part of VA's LCSCDP, few felt that the materials influenced their decision and many found them unintelligible. Some felt that printed materials were a better way for providers to communicate information without being condescending: "I thought it was better through the printed information because you don't really need a doctor talking to you with common sense you know, and you don't need to be talked to like a child. You can read the information for yourself on your own time and you're gonna solve the information. I really wouldn't appreciate a medical person sitting up there talking to me when I already know what I'm doing is crazy, I already know that so he doesn't need to repeat it to me."

At best educational materials were regarded as personally unimportant: "I guess I am not much of a reader of literature but I will listen to a doctor talk". At worst, patients considered the materials as "harsh" or "scary" because they expressed the relatively high likelihood of false positive findings, and a few expressed wanting this information to be conveyed in "a little softer" way. Conversely, most felt that the conversations with their physician were more influential, and preferred information provided this way, though some acknowledged that other patients might find the print numerical information helpful in their decision-making. A unique benefit of printed materials that some participants acknowledged was as a record of the information that was discussed for their reference following the visit.

Discussion and Conclusion

Discussion

We found that patients at high risk for lung cancer offered LCS at a routine primary care visit were poorly informed about LCS overall and both greatly overestimated the potential early detection benefits of LCS as well as underestimated and minimized potential harms of LCS. Emotional responses of fear, shame, and guilt compounded patients' misunderstandings about the ability of screening to quantify their lung cancer risk, and lack of interest in numerical information and a preference to defer decisions to their providers further diminished patients' comprehension necessary for informed decision-making.

Patient perspectives about LCS is an active area of research as clinicians and screening programs seek ways of communicating with patients to promote informed decision-making and facilitate smoking cessation. Our findings are consistent with previous studies that have found that patients are generally enthusiastic about LCS, despite being unaware of many important potential risks and holding unrealistic expectations about benefits [13, 15, 27, 41–46]. Our findings also align with research exploring barriers to decision-making posed by low patient numeracy and health literacy [47–49], and patient passivity and compliance [50, 51]. Our study also builds on findings that patients misunderstand and may need help recognizing potential harms of screening tests, and that many beliefs about screening that may go unrecognized in clinical settings can have profound influence on informed decision-making [52–55].

Decision-making about LCS involves weighing complex trade-offs between uncertain risks and benefits. Smokers made decisions not based on a mental calculus of these trade-offs, but instead on selective understanding of risks and benefits distorted by feelings aroused by the offer of screening and the recommendations and interpersonal relationships with their primary care physician. Emotions may be a critical influence on smokers' tolerance of uncertainty, which has been suggested as an influence on how patients view and weigh risks of benefits and harms of LCS [56].

Shared decision-making and use of decision aids are thought to be important for promoting informed decision-making as well as avoiding conveying a "license to smoke" and thus paradoxically deterring smoking cessation [4, 57]. These findings shed new light on how factors that are important to smokers influence decision making, which may be underappreciated by traditional medical decision-making models that emphasize logical and cognitive evaluations of risk information over patients' subjective experiential, implicit, and affective assessments of information in arriving at their choices [24, 58]. Health behavior scientists have increasingly emphasized social and emotional factors that interact with cognitive biases to affect health-related decisions [58, 59]. These interactive effects on decision-making may be unique to patients who continue to smoke, though may share similarity with other low-quality or mistaken patient decisions such as those to refuse vaccination or inappropriately undergo routine cancer screening [30, 55, 60, 61]. More research is needed to understand the decision-making processes of smokers and how decision-making studies in other research areas can inform LCS to achieve optimal patient and population outcomes.

This study has several limitations. Participants were asked to recall the offer of screening and subsequent discussions with their physician, which may be limited by recall bias and the accuracy of participants' memories. We examine patients' experiences only, which may not accurately reflect how physicians offered and discussed screening with patients. Further, the interview guide was designed to generate discussion about smokers' decision-making about LCS generally; future research examining shared or informed decision-making should specifically query participants about each element considered to be essential for patients making informed or shared decisions. Finally, by design, qualitative research has limited generalizability; this sample may be specifically

limited due to overrepresentation of white men, and some of these findings may be confounded by sociodemographic factors of VA patients who tend to be of lower SES and educational attainment and may have poorer health literacy than those found in primary care settings outside the VA. Additional research is needed to quantify the prevalence of these barriers and influence on decisional, clinical, and population outcomes.

Conclusion

Our investigation found unique cognitive, emotional, and social factors that influenced the decision-making experiences of current smokers when offered LCS in routine primary care at seven geographically diverse VA medical centers. Current smokers displayed biased understanding of the risks and benefits of LCS as a result of emotion-driven and uninformed decision-making. These findings enhance knowledge of barriers to informed decision-making about LCS experienced by smokers seen in primary care. Engaging smokers in shared and informed decisions about LCS may not be straightforward. The emotional, social, and cognitive barriers to informed decision-making identified in this study may require unique interventions tailored to the needs of smokers to improve decision-making processes for smokers as LCS is widely implemented into routine care.

Practice Implications

In the next few years, over 900,000 Veterans are estimated to be eligible for annual LCS as recommendations for screening are implemented and widely disseminated across health care systems. During this time, both clinicians and public health professionals may benefit from awareness of the barriers identified in this study. Specifically, primary care providers who offer LCS should be aware that smokers' decision-making may not be informed about accurate understanding of risks and benefits, though their considerable interpersonal influence may be critical in helping smokers to arrive at more informed decisions. Physicians may want to consider different ways to involve smokers in an explicit shared decision-making process, though it is notable that all elements generally considered essential for informed decision-making were not found in patients' accounts of the offer of LCS and subsequent decisions [62]. These elements, though not specifically queried by the interview guide, may be difficult to accomplish during congested and time-pressured primary care office visits, though additional research is needed to determine how systematically assuring these elements would alter the decision-making processes and outcomes of heavy smokers [63]. Thus, allowing ample time for smokers to understand the decision to be made about screening and discuss the risks and benefits may be one way to improve understanding and support informed decision-making. However, primary care providers may play a unique role in resolving these potential barriers, such as assisting patients in accurately understanding the purpose and utility of health care services (e.g., screening as opposed to diagnostic procedures), or recognizing the presence of strong emotions or nonmedical influences that may interfere with information processing and decision-making [62]. Current and future decision support tools may need to be adapted to convey risk and benefit information to current smokers in alternative ways.

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Compliance with Ethical Standards

All study procedures were reviewed and approved by the VA Puget Sound Health Care System Institutional Review Board and the University of Washington Institutional Review Board. All participants returned signed written informed consent forms by mail before the interviews were conducted.

Classifications Health Literacy; Secondary-Screening; Smoking Cessation; Qualitative.

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