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What factors do patients consider most important in making lung cancer screening decisions? Findings from a demonstration project conducted in the Veterans Health Administration

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ABSTRACT

Introduction: The National Lung Screening Trial recently reported that annual low-dose computed tomography screening is associated with decreased lung cancer mortality in high-risk smokers. This study sought to identify the factors patients consider important in making lung cancer screening (LCS) decisions, and explore variations by patient characteristics and LCS participation.

Material and methods: This observational survey study evaluated the Minneapolis VA LCS Clinical Demonstration Project in which LCS-eligible Veterans (N = 1388) were randomized to either Direct LCS Invitation (mailed with decision aid, N = 926) or Usual Care (provider referral, N = 462). We surveyed participants three months post-randomization (response rate 44%) and report the proportion of respondents rating eight decision-making factors (benefits, harms, and neutral factors) as important by condition, patient characteristics, and LCS completion.

Results: Overall, the most important factor was personal risk of lung cancer and the least important factor was health risks from LCS. The reported importance varied by patient characteristics, including smoking status, health status, and education level. Overall, the potential harms of LCS were reported less important than the benefits or the neutral decision-making factors. Exposure to Direct LCS Invitation (with decision aid) increased Veterans' attention to specific decision-making factors; compared to Usual Care respondents, a larger proportion of Direct LCS Invitation respondents rated the chance of false-positive results, LCS knowledge, LCS convenience, and anxiety as important. Those completing LCS considered screening harms less important, with the exception of incidental findings.

Conclusion: Decision tools influence Veterans' perceptions about LCS decision-making factors. As the factors important to LCS decision making vary by patient characteristics, targeted materials for specific subgroups may be warranted. Attention should be paid to how LCS incidental findings are communicated.

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1. Introduction

Lung cancer is the leading cause of cancer morbidity and mortality in the United States [1]. Although prevention is the most effective strategy for reducing the burden of lung cancer, lung cancer screening (LCS) improves early detection of lung cancer. The National Lung Cancer Screening Trial (NLST), the largest trial to date, showed a 20.0% reduction in lung cancer mortality using annual low-dose computed tomography (LDCT) compared with chest X-ray [2]. The U.S. Preventive Services Task Force subsequently incorporated these results into revised LCS guidelines recommending annual LDCT for adults aged 55–80 who are current smokers or former smokers who have quit within the past 15 years, with a 30 pack-year smoking history [3]. Several professional orga-

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nizations have issued similar recommendations [4–8], all of which promote shared decision making for LCS.

The emphasis on shared decision making reflects the fact that while LDCT-based LCS has the possibility to decrease mortality from lung cancer, the NLST and multiple European trials demonstrated potential harms that are increasingly debated [9,10]. These harms include: false-positive results, ranging from 70.2% [11] to 96.4% [2]; radiation exposure, although the individual effective dose is very low [12]; and incidental findings (i.e., clinically significant abnormalities not suspicious for lung cancer), identified in 7.5% of all NLST scans [2]. Evaluations of adverse psychosocial consequences have varied [13], although trials have shown unfavorable outcomes (e.g., poorer quality of life, higher cancer distress) in patients receiving an indeterminate screening result at short-term follow up only [14,15]. Despite the harms outlined above, studies consistently report that patients are enthusiastic about LCS; 82% of surveyed primary care outpatient clinic patients [16] and 93% of Veterans reported they would undergo LCS if recommended by their physicians [17]. However, participation is often influenced by patient sociodemographics [16,18,19; Lillie unpublished], smoking status [18,20,21], and previous experiences with hospitals and doctors [20]. Few studies have characterized patient attitudes towards LDCT and the individual decision-making factors that patients find most important in making LCS decisions. This limited literature found the following factors to be significant in LCS decision making: early detection of lung cancer [20], lung cancer risk perception [20], fear of cancer [22], fear of radiation exposure from CT scans [16], and skepticism towards screening [23].

To clarify the relative importance of factors to patients' decisions about LCS, we conducted an observational study to: (1) identify which factors patients consider most important in making LCS decisions; (2) explore whether factors considered important vary by patient characteristics; and (3) detect whether perceived importance of the benefits and harms of screening varied by LCS completion. Based on the existing literature outlined above, we hypothesized that there would be differences by individual-level factors such as smoking status, level of education, income, and health status. Variation by patient characteristics would suggest that targeted decision aids for specific subgroups are warranted, including values clarification exercises that help patients elucidate their own values and preferences during decision making.

2. Materials and methods

2.1. Setting, participants and procedures

For this observational study, we conducted a survey evaluation of one facility (Minneapolis VA Health Care System [MVAHCS]) participating in the Veterans Health Administration (VHA) Lung Cancer Screening Demonstration Project. This demonstration project was initiated by the VHA National Center for Health Promotion and Disease Prevention to assess the feasibility of an evidence-based LDCT-based LCS program at eight VHA sites [24,25].

The MVAHCS quality improvement demonstration project used a national VHA electronic health record (EHR) algorithmic search to identify patients meeting the US Preventive Services Task Force LCS criteria at the time of an appointment with their primary care provider (PCP). If a patient met the inclusion criteria, the algorithm activated a prompt in the EHR for the clinic appointment check-in nurse to obtain tobacco pack year (TPY) information from the patient (current cigarette smoking status, years smoking, and average cigarettes per day). The full MVAHCS Lung Cancer Screening Demonstration Project methodology is available elsewhere (Fabbrini under review). In brief, between 01/02/2014 and 08/15/2014 the MVAHCS demonstration project took all eligible patients and randomly allocated them at a 2:1 ratio to: (1) Direct LCS Invitation or (2) Usual Care under the PCP (no Direct LCS Invitation but possible LDCT referral as part of usual care). The patients in the Direct LCS Invitation group received the mailed *Screening for Lung Cancer* brochure (see Supplementary material) [26], a VHA-developed LCS decision aid, and an invitation letter to call the LCS coordinator for a discussion about screening and to schedule an LDCT, with or without additional phone calls. The decision aid provided detailed information about the screening process, the benefits and potential harms, including false-positive results and complications from further testing, and a values clarification exercise. Patients in Usual Care did not receive the mailed decision aid or invitation, but were exposed to annual smoking cessation clinical reminders. All patients had access to the comprehensive MVAHCS Tobacco Cessation Program, which includes assessments of smoking status via a clinical reminder, patient education materials, individual and group behavioral therapy, and pharmacotherapy.

We administered surveys to patients in both conditions three months after randomization using a modified Dillman methodology [27]. We mailed a survey packet containing a study invitation letter, a self-administered survey, and a postage-paid return envelope. After 21 days non-respondents received a second survey packet. Veterans were mailed a $10 check for survey completion as compensation for their time and effort. This observational survey study was approved by the MVAHCS Institutional Review Board.

2.2. Measures

To identify factors respondents considered important to LCS decision making, we asked Veterans to rate the following eight factors with respect to their importance in the decision-making process: 1) lung cancer risk, 2) fear of lung cancer, 3) chance of incidental findings, 4) convenience of LCS, 5) chance of a false positive result, 6) anxiety of waiting for the LDCT results, 7) knowledge of LCS, and 8) health risks of the LDCT itself. Respondents rated the importance of each factor on a 5-point Likert scale: 1 = 'not at all important', 2 = 'slightly important' 3 = 'neutral', 4 = 'moderately important', 5 = 'extremely important'.

Self-reported Veteran characteristics we assessed included: race/ethnicity; highest education attainment; annual household income; employment status; overall health (poor, fair, good, very good, excellent); knowing someone who had lung cancer (spouse/partner, family member, close friend, casual acquaintance, no); and knowing someone who had LCS (yes, no). We collected age, gender, smoking status and TPY information from the clinical reminder, and LCS completion dates from VHA medical records. We defined LCS completion as an LDCT that was completed before the survey return date.

2.3. Statistical analyses

We used descriptive statistics to characterize importance ratings overall, across conditions and across subgroups. We used Wald chi-square statistics to examine whether the proportion of respondents reporting a factor to be moderately or extremely important (rated 4 or 5 on Likert scale) varied between the following groups: current vs former smokers; respondents with less than or equal to a high school education vs those more educated (i.e., with at least some college education); respondents with an income >$40,000 vs those with an income ≤$40,000; and respondents with good/very good/excellent health vs poor/fair self-reported health. We also compared the Direct LCS Invitation group vs Usual Care Veterans to assess whether exposure to the *Screening for Lung Cancer* brochure changed how respondents valued the different factors. We then focused on those in the Direct LCS Invitation only group to compare the proportion reporting a factor to be very or extremely