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Lung Cancer Screening Uncertainty among Patients Undergoing LDCT

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Abstract

Objectives—Lung cancer is the leading cause of cancer death, yet lung screening remains underutilized. Lung cancer screening uncertainty (LCSU), including referral clarity and the perceived accuracy of screening, may hinder utilization and represent an unmet psychosocial need. This study sought to identify correlates of LCSU among lung screening patients.

Methods—Current and former smokers (N = 169) completed questionnaires assessing LCSU, sociodemographic variables, objective and subjective numeracy, stress, and anxiety, as part of a cross-sectional study of lung screening patients at an academic hospital.

Results—Patients (52% current smokers) reported high clarity about the reason for their lung screening referral. Less clarity was associated with lower education, not receiving Medicare, and greater stress and anxiety. Patients perceived lung screening to be moderately accurate, and levels were inversely related to objective numeracy. Subjective numeracy was higher among former versus current smokers (OR = 2.5), yet was unrelated to LCSU variables.

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Conflicts of Interest Disclosure Statement
All authors of this article declare they have no conflicts of interest.

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Conclusions—Several sociodemographic, numeracy, and emotional factors were associated with greater LCSU. With multiple policy and clinical guidelines purporting the uptake of annual lung screening, it is important to identify patients with LCSU and tailor shared decision-making to clarify their uncertainties.

Keywords

screening; lung cancer; uncertainty; health communication

The utilization of lung screening with low-dose computed tomography (LDCT) potentially saves or prolongs lives for those at high risk for lung cancer, the leading cause of cancer death worldwide.[1,2] Only 15% of lung cancers are diagnosed at early stages, when curative treatments are most effective.[3] Fortunately, results from the National Lung Screening Trial (NLST) found a 20% relative risk reduction in lung cancer mortality and a 6.7% reduction for all-cause mortality among patients at high risk for lung cancer [ie, 55–74 years old with a significant (≥30 pack-years) and recent (within 15 years) smoking history] who underwent 3 annual LDCT screens as compared to those who only received chest X-rays.[2] Subsequent studies also have demonstrated the utility of LDCT for current and former heavy smokers.[4,5] Annual screening is now supported by numerous health agencies, including the US Preventive Services Task Force (USPSTF), National Comprehensive Cancer Network (NCCN), American Cancer Society (ACS), American Thoracic Society, and American College of Chest Physicians.[6–9] These organizations' guidelines for screening eligibility are generally consistent[10] with those of the Centers for Medicare & Medicaid Services (CMS)[11] based on recommendations from the USPSTF[6] and findings from the NLST.[2] As of early 2015, the CMS has covered annual lung screening for patients at high risk,[11] a landmark decision meant to dramatically increase early detection of lung cancer. Still, rates of lung screening are low, with underscreening related to approximately 12,000 lung cancer-related deaths per year.[12] Thus, it is critical to understand factors that may impede the acceptability and feasibility of LDCT among current and former heavy smokers.

In recognition of this need, there have recent been calls for increased research on the "uncertainties of screening" in lung cancer.[13] Findings, primarily from qualitative studies, point to a lack of knowledge about LDCT and uncertainty about its personal relevance among lung screening patients.[14,15] This may be due to variability in adoption of lung cancer screening guidelines,[10,16] concerns about its cost-effectiveness,[17] high rates of comorbidities among patients undergoing this testing,[18] and the substantial number of false positives.[2] Thus, it is likely that lung screening patients may not fully understand why a LDCT is recommended or doubt whether its results are accurate.

Cancer-related uncertainty can arise when patients do not understand a testing procedure, its potential benefits and risks, or how its results might inform treatment.[14,19] Importantly, it has been associated with disruptions in emotional functioning, sleep, and energy,[20] and it also may lead to taking greater risks with health decisions.[14,21] In the context of cancer screening, uncertainty may lead to avoidance of follow-up visits[19,22,23] or refusal of tobacco treatment services,[8] potentially placing lung screening patients at risk for poorer health outcomes.[12,14] Collectively, uncertainty in the context of lung cancer screening may be

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unpleasant for patients and could have potential downstream consequences for non-adherence to annual screening guidelines. To date, *lung cancer screening uncertainty* (LCSU) has not been measured, limiting the investigation of its correlates and implications.

Drawing from Mishel's Uncertainty in Illness Theory[19] and Han, Klein, and Arora's taxonomy of uncertainty in healthcare,[24] we conceptualized LCSU as comprising patients' clarity about why they are undergoing lung screening (ie, referral clarity) and their perceptions about its accuracy. LCSU may differ between current and former smokers, as these groups have been found to have different appraisals of risk for lung cancer and attitudes about cancer screening.[15,25] Findings from the NLST baseline data indicate that whereas greater perceived risk for lung cancer is associated with greater worry among both current and former heavy smokers, these ratings are significantly lower for the latter group.[25] Interestingly, both groups had unique patterns of overestimating certain risks and underestimating others, suggesting gaps in their understanding of the utility of lung screening and the importance of early detection. This suggests that current and formers smokers may have differential uncertainties regarding lung cancer screening. In addition to smoking status, sociodemographic characteristics and health literacy could be examined as correlates of LCSU. For instance, greater education and, relatedly, higher objective numeracy can promote understanding of the purpose and accuracy of general[26] and certain cancer-specific diagnostic procedures,[27,28] though to date, these associations have not been examined in lung screening.

The present study aimed to provide an initial examination of LCSU among patients undergoing LDCT. Specifically, this investigation sought to: (1) quantify 2 components of LCSU (referral clarity and perceived accuracy); (2) identify sociodemographic, medical, smoking behavior, and numeracy correlates to LCSU; and (3) demonstrate associations between LCSU and emotional functioning. All aims were examined explicating by smoking status.

METHODS

Study Design

As the overall intent of this paper was to improve understanding of the experiences of patients undergoing lung cancer screening, participants were self-identified as current or former smokers who received a LDCT scan at a pulmonary nodule clinic at Massachusetts General Hospital or one of its satellite primary care practices.

Recruitment and Enrollment

From August 2014 to January 2016, eligible participants undergoing a LDCT scan were identified. Within one week of the LDCT appointment, study research staff mailed patients a study information flyer and an opt-out letter. The opt-out letter instructed patients to contact research staff, via telephone number or email, within 7 days of receipt of the letter if they did not wish to participate. Patients who did not opt-out were contacted by a research team member to discuss study participation. Consent procedures were completed via phone.

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We mailed surveys to 567 patients identified through electronic medical record who were scheduled for lung screening. Of these patients, 120 (21%) opted out (active withdrawal) and 278 (49%) did not return the survey despite our follow-up attempts as described above (passive withdrawal). Thus, our final sample included 169 (30%) lung cancer screening patients.

Data Collection

Participants were given the option to complete the survey using 4 different modalities: via email, mailed paper packet, completion over the phone, and via electronic tablet. Most participants completed the survey via e-mail (61%), followed by paper packet (34%), telephone call (4%), and electronic tablet (1%).

Measures

Sociodemographic, medical, and smoking history variables—The self-report questionnaire included the following measures of sociodemographic characteristics: age, sex, education, race and ethnicity, marital status, number of children, and insurance provider(s).

Additionally, items assessed medical history (family history of lung cancer, personal history of cancer or smoking related disease [SRD]), smoking status ([“Did you smoke a cigarette (even one puff) in the past 30 days?” – yes/no responses identified respondents as current or former smokers, respectively]), number of years quit (if applicable), average number of cigarettes per day, and years of smoking.

Lung cancer screening uncertainty (LCSU)—As there are no extant measures of lung screening uncertainty, we developed items by adapting questions used previously in oncology populations. To measure *referral clarity*, patients were asked about their understanding of why they were undergoing lung screening [“Is it clear to you why you have had a computed tomography (CT) scan of the lungs?”] which was adapted from a measure of reactions to treatment among breast cancer patients.[29] Response options ranged from 1 = Not at all clear to 4 = Extremely clear. Patients also rated their *perceived accuracy* of screening (“How accurate do you think lung cancer screening is?”) which was used in the NLST[25] and has been adapted for use with other cancer screening populations.[30] Response options ranged from 1 = Not at all to 5 = Extremely.

Numeracy—Numeracy was assessed using 2 items from the Subjective Numeracy Scale[31] for which normative data were available through the Health Information National Trends Survey (HINTS).[32] Preference for numeric information (ie, *subjective numeracy*) was assessed with the item (“When people tell you the chance of something happening do you prefer they use words or numbers?”) Response options were “Prefer words,” “Prefer numbers,” and “No preference,” which were dichotomized to indicate a preference for numbers (yes vs no). HINTS results indicate that 45.6% of the general US adult population endorses a preference for numbers.[33] The ability to understand numeric information conferring risk (ie, *objective numeracy*) was assessed with the item, (“Which of the following numbers represents the biggest risk of getting a disease?”) Response options were

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"1 in 100," "1 in 1000," and "1 in 10." HINTS findings suggest that 77.5% of the general US adult population correctly answers this item.[33]

Emotional functioning—Perceived stress was measured using the 4-item Perceived Stress Scale (PSS-4).[34] Items asked patients to recall how frequently they have experienced psychosocial difficulty over the past month. Responses were presented on a 5-point Likert scale ranging from 0 ("Never") to 4 ("Very Often"). Cronbach's alpha in this sample was good (α=.74).

Anxiety was assessed using the GAD-2.[35] Two items assessed the frequency of anxiety symptoms on a 4-point Likert scale ranging from 0 ("Not at all") to 3 ("Nearly every day"). Items are summed to create a total continuous score, with scores of 3 or higher indicating elevated anxiety.[35]

Data Analysis

Data were analyzed using SPSS v24. All variables were examined for normality. Non-parametric analyses were used with any variables exhibiting large skew (> 3.0) and/or large kurtosis (> 8.0). Summary statistics were computed and compared between current and former smokers. Pearson and Spearman correlations examined associations between continuous/ordinal variables. Analyses of association between binary variables and among multi-categorical variables were conducted using odds ratios with 2-tailed Fisher exact or Pearson chi-square tests, respectively. Group differences with continuous outcomes were analyzed using independent samples t-tests, Wilcoxon Rank Sum Z-tests, and Kruskal-Wallis chi-square tests. Multivariate regression models tested the unique contributions LCSU variables on emotional functioning while controlling for smoking status.

RESULTS

Sample Characteristics

Respondents included 169 patients (52% current smokers and 48% former smokers) with an average age of 64 years and 51% female (Table 1). Whereas 18% of patients had a history of any cancer, one-third endorsed having a family history of lung cancer. On average, patients had smoked close to one pack per day for 42 years, accruing an average of 39 pack-years.

Comparison of current and former smokers—Current and former smokers presenting at LDCT were similar in most sociodemographic and medical characteristics (Table 1). However, current smokers were over 3 times as likely be insured through Medicaid ($p = .01$), had a significantly higher rate of stroke history ($p = .03$), had fewer overall pack-years ($p = .03$), and had higher levels of perceived stress ($p < .001$) and anxiety ($ps < .01$).

Almost half of all patients reported having a numeracy preference. As compared to current smokers, former smokers were over twice as likely to prefer numbers when conveying risk ($p = .005$). When objective numeracy was reviewed, most of the sample correctly identified the fraction representing the highest risk, with no differences based on smoking status ($p = .15$).

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Lung cancer screening uncertainty—Overall, patients tended to report a high degree of referral clarity and perceived lung screening to be moderately accurate. Both LCSU variables were positively correlated with one another (Spearman's r = .20, p = .04). Referral clarity was comparable between current and former smokers (Mean rank of former smokers = 60.08, Mean rank of current smokers = 52.28, Z = − 1.72, p = .09), as were levels of perceived accuracy [t(163) = 0.09, p = .93].

Greater referral clarity was associated with more education [$\chi^2(3) = 10.89$, p = .01] and having Medicare (Z = 1.98, p < .05). Referral clarity was unrelated to any medical conditions (p*s* > .05), objective numeracy (Spearman's r = .03, p = .77), and subjective numeracy (Spearman's r = .002, p = .98).

Higher referral clarity was associated with lower levels of stress (Spearman's r = − .19, p = .048) and anxiety (Spearman's r = − .23, p = .02*;* Mean rank of high anxiety = 45.73, Mean rank of low anxiety = 58.52, Z = − 2.40, p = .02). After controlling for smoking status, the association with anxiety did not change (continuous anxiety score β = − .23, p = .02; clinically elevated anxiety β = − .22, p = .02), but it did weaken the relation with perceived stress (β = − .13, p = .16).

Ratings of the perceived accuracy of LDCT were unrelated with the sociodemographic, medical, and smoking behavior variables, p*s* > .05. Less perceived accuracy was associated with higher scores of objective numeracy (Pearson's r = − .18, p = .02), but not subjective numeracy (Pearson's r = .04, p = .59). Perceived accuracy scores were not related with indices of emotional functioning (stress, Pearson's r = −.08, p = .34; anxiety continuous score Pearson's r = .05, p = .56; clinically elevated anxiety Pearson's r = .04, p = .61*)* in adjusted and unadjusted analyses.

DISCUSSION

Given the efforts to increase the uptake of lung screening, it is imperative to understand patients' perceptions of the lung screening experience.[36] To clarify the role of LCSU in lung screening behavior in a naturalistic setting, this study sought to examine levels of uncertainty among lung screening utilizers, among whom we hypothesized uncertainty levels would be low. Overall, findings are encouraging in that patients understood the reason for their lung screening referral and perceived LDCT to be moderately accurate.

Several key correlates emerged with patients' ratings of LCSU. Referral clarity levels were higher among patients with Medicare and among those with higher education. Since providing coverage for annual screening in 2015, CMS has reached out to eligible patients with information about lung screening in the form of routine flyers and an online portal with resources for screening locations. Additionally, educational attainment can bolster patients' understanding in treatment planning, which may be driven by health literacy.[28] Findings also highlighted the emotional impact of lacking clarity about the purpose of undergoing lung screening. Patients with low referral clarity reported having anxiety at clinically elevated levels. These results are consistent with previous qualitative findings[15] and suggest the utility of a single-item measure to detect distress among lung screening patients. In contrast,

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patients' perceptions of the accuracy of LDCT were unrelated to emotional distress. The only correlates with ratings of perceived accuracy were objective numeracy levels, which were inversely related. This finding suggests that patients who readily understand numeric information may have more questions about the sensitivity and specificity of LDCT to detect and identify suspicious nodules. These patients also may be more likely to have concerns about false-positive results, incidental findings, and indeterminate screening results.

Findings from this study have implications for shared decision-making prior to screening and communication about follow-up recommendations. These patient-provider interactions offer a window into patients' values, expectations, preferences, and needs, as well as opportunities to intervene on any concerns. Because the potential benefits and harms of LDCT are nuanced, attention should be paid to tailor these conversations to enhance patient understanding. For instance, assessing numeracy during clinical encounters is feasible and acceptable,[37] and it may help reduce uncertainty through matching information with patients' preferences.

This study had several strengths and limitations. Questions assessing LCSU were theoretically driven and quantifiable, which will facilitate future comparisons of screening uncertainty in other patient populations. Measures of LCSU variables and numeracy were limited to single items, precluding our ability to assess internal reliability of these factors. Data in this study were cross-sectional, and studies utilizing longitudinal data are needed to elucidate the potential impact of shared decision-making conversations on LCSU. Because participants were identified after being scheduled for LDCT, we acknowledge that these findings may not describe the uncertainties and characteristics of all high-risk adults, especially those not engaged in routine care or whose physicians are unaware of lung screening eligibility guidelines. Finally, patients were recruited from a large hospital in the Northeast, which limits the generalizability of these findings to smaller hospitals and those in other geographic regions.

In response to a call for the study of LCSU,[13] the present study offers early insights into LCSU by examining referral clarity and perceived accuracy. Clinicians should assess these factors during shared decision-making and, taking patients' smoking status, education, and numeracy preferences into account, tailor their conversations to communicate the benefits and risks of LDCT more clearly.

Human Subjects Approval Statement

This observational, cross-sectional study was approved by the human subjects committee at Massachusetts General Hospital. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

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Table 1

Summary of Patient Characteristics

	Total (N = 169)	CS[a] (N = 88)	FS[b] (N = 81)	OR (95% CI)	p
Sociodemographic Variables					
Age, M (SD)	64.35 (6.21)	63.87 (5.79)	64.88 (6.64)	–	.29
Sex (female), N (%)	84 (50.60%)	38 (43.70%)	46 (58.20%)	1.79 (0.97,3.33)	.07
Education, N (%)					
<HS[c] graduate	7 (4.20%)	6 (6.90%)	1 (1.30%)	5.78 (0.68,49.10)	.08
HS[c] graduate/GED	38 (22.90%)	24 (27.60%)	14 (17.70%)	1.77 (0.84,3.72)	.20
Post HS[c]	50 (30.10%)	24 (27.60%)	26 (32.90%)	1.10 (0.56,2.13)	.50
College and beyond	71 (42.80%)	33 (37.90%)	38 (48.10%)	0.66 (0.36, 1.22)	.21
Race/ethnicity, N (%)					
Non-Hispanic White	158 (95.20%)	83 (96.50%)	75 (94.90%)	0.83 (0.18, 3.83)	.48
Black	5 (3.00%)	2 (2.30%)	3 (3.70%)	0.60 (0.10, 3.71)	.67
Other	6 (3.60%)	3 (3.30%)	3 (4.91%)	0.92 (0.18,4.68)	
Marital Status, N (%)					
Married/partnered	97 (58.10%)	49 (55.70%)	48 (60.80%)	0.86 (0.47, 1.59)	.53
Single	24 (14.40%)	15 (17.00%)	9 (11.40%)	1.60 (0.66, 3.89)	.38
Widowed	8 (4.80%)	3 (3.40%)	5 (6.30%)	0.52 (0.12,2.26)	.49
Divorced/separated	38 (22.80%)	21 (23.90%)	17 (21.50%)	1.14 (0.55,2.36)	.85
Children (at least one), N (%)	120 (71.90%)	59 (67.00%)	61 (72.20%)	0.60(0.30, 1.20)	.17
Health Insurance, N (%)					
Private	86 (50.90%)	41 (46.60%)	45 (55.60%)	1.09 (0.60, 1.99)	.28
Medicare	80 (47.30%)	41 (46.60%)	39 (48.15%)	1.06 (0.58, 1.95)	.88
Medicaid/Mass Health	35 (20.70%)	27 (30.70%)	8 (9.80%)	**3.31 (1.34, 8.29)**	**.01**
Military/Tricare/VA[d]/Champ-VA[d]	4 (2.40%)	3 (3.40%)	1 (1.20%)	2.83 (0.29,27.71)	.62

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	Total (N = 169)	CS[a] (N = 88)	FS[b] (N = 81)	OR (95% CI)	p
Medical Variables					
History of chronic illness, N (%)					
Asthma	31 (20.70%)	15 (19.70%)	16 (21.60%)	0.89 (0.40,1.97)	.84
COPD[e]	49 (31.20%)	28 (34.10%)	21 (28.00%)	1.33 (0.68,2.63)	.50
Diabetes	19 (12.60%)	10 (13.20%)	9 (12.00%)	1.11 (0.42,2.91)	.10
Heart disease/Heart attack	28 (17.90%)	13 (16.30%)	15 (19.70%)	0.79 (0.35, 1.79)	.68
Hypertension	88 (55.30%)	45 (54.20%)	43 (56.60%)	0.90 (0.49,1.70)	.87
Stroke	5 (3.40%)	5 (6.60%)	0 (0%)	**5.07 (0.58,44.50)**	**.03**
Personal cancer history	20 (17.90%)	18 (20.50%)	12 (14.81%)	1.46 (0.65,3,25)	.42
Family history of lung cancer	55 (33.30%)	28 (32.60%)	27 (33.33%)	0.93 (0.49,1.78)	.87
Smoking-Related Variables					
Years smoked, M (SD)	42.65 (10.16)	46.06 (7.89)	38.84 (11.06)	–	**<.001**
Cigarettes per day, M (SD)	19.82 (13.91)	15.41 (9.42)	25.03 (16.41)	–	**<.001**
Packs per day, M (SD)	0.99 (0.70)	0.77 (0.47)	1.25 (0.82)	–	**<.001**
Pack-years, M (SD)	39.26 (23.66)	35.44 (21.84)	43.90 (25.08)	–	**.03**
Emotional Functioning					
Perceived stress, M (SD)	5.14 (3.35)	6.01 (3.46)	4.16 (2.93)	–	**<.001**
Anxiety - continuous, M (SD)	1.62 (1.78)	2.03 (1.94)	1.16 (1.46)	–	**.001**
Anxiety - elevated, N (%)	43 (26.06%)	30 (34.09%)	13 (16.05%)	**2.71 (1.29, 5.67)**	**.008**
Numeracy					
Subjective numeracy, N (%)	72 (44.20%)	28 (33.30%)	44 (55.70%)	**0.39 (0.21,0.75)**	**.005**
Objective numeracy, N (%)	133 (82.10%)	66 (77.60%)	67 (87.00%)	0.52 (0.22,1.20)	.15
Lung Cancer Screening Uncertainty					
Referral clarity, Median (10%, 25%, 75%)	4 (3, 4, 4)	4 (3, 3, 4)	4 (3, 4, 4)	–	.09
Perceived accuracy, M (SD)	3.76 (0.72)	3.75 (0.77)	3.83 (0.38)	–	.93

Note.

[a]CS = Current smokers

[b]FS = Former smokers

[c]HS = High school

[d]VA = Veterans Affairs

[e]COPD = Chronic obstructive pulmonary disease

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