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Perceptions of lung cancer risk and beliefs in screening accuracy of spiral computed tomography among high-risk lung cancer family members

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Abstract

Objective—Spiral computed tomography (SCT) is being evaluated as a screening tool for lung cancer. Our objective was to describe the effect of participation in SCT screening on participants' risk perceptions, worry, and expectations regarding the accuracy of the screening result.

Methods—We surveyed sixty individuals with lung cancer family history who were participating in a SCT study for the primary purpose of improving genetic linkage analysis at baseline, and then 1 and 6 months post SCT.

Results—Of the sixty participants, forty received normal results, nineteen received non-negative results requiring follow-up, and one was diagnosed with lung cancer. At baseline, participants reported high levels of perceived lung cancer risk (64%), were concerned about getting lung cancer (94%) and the majority (84%) were not OK with receiving a non-negative SCT result. At 1 month post SCT, those with a non-negative screen (n=19) had lowered their expectations of test accuracy

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Conflict of Interest

The authors declare there is no conflict of interest.

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regarding non-negative results (54%) and reported increased levels in worry/concern (100%) and perceived risk (75%), but these effects diminished over time and returned almost to baseline levels at 6 months.

Conclusions—Persons at very high empiric risk for lung cancer expect their SCT screening test to be accurate and present with high levels of lung cancer risk perception and worry/concern overall. Our findings suggest a need for risk counseling and discussion on the limitations of screening tests to accurately detect lung cancer.

Keywords

spiral computed tomography; lung cancer; screening; psychosocial oncology

Introduction

Lung cancer is the leading cause of cancer death in the United States among both men and women (1). It is estimated that an individual's risk of developing lung cancer doubles if they have a first degree relative with lung cancer (2,3). While the 5-year relative survival rate for all stages of lung cancer combined remains at 15%, a more promising survival rate of 50% is shown among patients diagnosed with localized early stage disease (1). Early stage lung cancer is largely asymptomatic, and as a result, the disease is usually diagnosed at advanced stages when prognosis is poor. Unfortunately, current methods of lung cancer screening have not proven effective in detecting asymptomatic lung cancer and are not recommended(4,5). However, individuals with a significant family history of lung cancer present a select high-risk group who could benefit from early screening and detection.

Recent advances in screening technology, such as spiral computed tomography (SCT), could improve survival rates, as it has exhibited promising results in detecting early stage (Stage I) lung cancer (6–9). However, there is still much debate over the results of these initial studies (10), including concerns about the high proportion of “non-negative results” (lesions detected that require further follow-up to determine whether or not they are cancerous) and increases in the overall costs of screening (11). In the Mayo Clinic Lung SCT study of smokers from the general population (9), 69% of participants were found to have “non-negative results” during the two years after baseline CT screening, and the majority of these were subsequently found to be benign after additional testing via follow-up SCT scans at 6 and 12 months.

Currently, little is known about what individuals expect regarding the accuracy of SCT screening and whether such expectations might change after undergoing an actual screening test. These factors may influence their attitudes and decision-making toward undergoing lung cancer screening prevention. For example, uncertainty regarding mammography recommendations has been associated with both diminished intentions to obtain a mammogram and lower intentions for obtaining a subsequent mammogram (12). Furthermore, results from a recent study by van den Berg and colleagues (13) showed that among current and former smokers who decided not to participate in the Nelson trial for lung cancer screening reported limited knowledge about lung cancer screening and expressed less positive attitudes towards lung cancer screening in comparison to those who participated. Ellsberg's theory on decision-making provides a concept of ambiguity that describes a type of uncertainty about the risk information at hand, relating specifically to the “reliability, credibility, or adequacy” of one's information concerning future outcomes (12,14). Perceived ambiguity about lung cancer screening accuracy refers to the potential future outcome of a test, which answers, “how good is the test at identifying people with the disease and people without the disease?” The answer to this question lies in the test's sensitivity (proportion of people with disease who have a positive test result) and specificity (proportion of people without disease who have a negative

test result). With SCT screening, a better understanding of expectations regarding the accuracy of a screening test is paramount, given the high rate of non-negative results.

In response to receiving a non-negative screening result individuals may experience an increase in fear and anxiety. A recent study by Byrne and colleagues (15) indicated no change over time in perceived lung cancer risk among individuals who received both negative and nonnegative SCT screening results. Furthermore, among those with a suspicious (non-negative) screening result the perceived risk of cancer and fear of cancer increased after screening but dissipated over time, while individuals with a negative screening result had a temporary reduction over time in perceived risk of cancer and little change in fear of cancer. Because overestimation of personal cancer risk and cancer related worry/concern are reported among individuals with a positive family history (16–21) understanding the psychological impact surrounding SCT screening beyond receptivity to smoking cessation (15,22–26), in which the risks and benefits are uncertain, among these individuals is a critical need and merits further investigation.

In the present study, we explored how participation in SCT lung cancer screening influenced expectations regarding the accuracy of a screening test, as well as, perceptions of perceived lung cancer risk and worry/concern among those having significant lung cancer family history. The parent study aimed to determine the efficacy of SCT screening in improving linkage analysis for Lung Cancer genetic research. Further understanding perceptions regarding test accuracy in the context of a test with yet to be proven efficacy could shed some light on the controversy surrounding the sensitivity and specificity of other cancer screening tests that are already recommended to the average risk population (3).

Methods

Study Population and Study Procedures

The study was approved by the Mayo Institutional Review Board. Recruitment occurred over a 14-month period between August 2001 and October 2002. Participants were identified and subsequently recruited through the Mayo Clinic Lung Cancer Genetic Epidemiology Registry. Eligible study participants: 1) were greater than age 30 years; 2) had no personal lung cancer history; 3) had a first degree relative with lung cancer in a kindred containing at least three blood relatives with lung cancer; and 4) had medical insurance. Participants were contacted by letter, and three contact attempts were made before characterizing a potential study participant as a non-responder. For the parent study that assessed the efficacy of SCT screening for high risk due to family history, the target sample was 60 family members. For this pilot study we included all 60 participants from that parent study. From the registry, 371 participants were identified as meeting the eligibility criteria as a high risk family member, 63 expressed an interest in participating, and 60 provided written consent to participate in the research SCT screening. Consenting participants were mailed surveys at baseline prior to research SCT screening, one month following receipt of their SCT result, and 6 months post-study after going through follow-up with the pulmonologist. In our study, all participants received their study results from one pulmonologist. He disclosed spiral CT results but explained that he avoided statistically-based discussions. Instead, he used commonly understood analogies to explain how the SCT works, and he specifically told his patients not to worry if they received a non-negative result. He said that, “If (the scan) detected something indeterminate, it would depend on its size.” I might say, “Let’s go every six or 12 months.” I would tell them, “‘It’s something I’m not real worried about, it’s probably benign but we need to keep an eye on it’.”

Measures

Demographic data were collected using a baseline questionnaire, which included participants’ age, gender, race-ethnicity, and the number of first degree relatives with lung cancer.

Tobacco use data were also collected by items on the baseline questionnaire (27). Participants were asked if they had smoked more than 100 cigarettes in their lifetime. Those who reported “no” to this question were classified as *never smokers*. Participants who reported smoking 100 or more cigarettes in their lifetime, but who had not smoked within the last 30 days, were categorized as *former smokers*. Those who smoked more than 100 cigarettes in their lifetime and had smoked within the past 30 days were classified as *current smokers*.

Expectations regarding the accuracy of lung cancer screening results was assessed using four Likert-style items developed by the investigators for this study (e.g., “It would be OK if a test detects less than 100% of people who have lung cancer,”) from “Strongly Agree” to “Strongly Disagree” and “I don’t know”). The questions were designed to address test sensitivity and specificity in a way that a lay audience could understand. The questions were worded both personally and globally whereby respondents were asked how they felt if it was their test versus a screening test in general.

Lung cancer risk perception was measured by two items developed by Lerman et al. (28) that asked about absolute and comparative lung cancer risk perception using a five-point Likert response format. The comparative lung cancer risk question asked “Compared to most people of your same age, sex, and race, what do you think your chances are of getting lung cancer sometime in your life?” The perceived absolute lung cancer risk question asked “How likely do you think you will get lung cancer sometime in your life?”

Lung cancer-related concern utilized four items adapted from Lerman, et al. (29) using a four point Likert response format to assess the degree of lung cancer worry/concern among the participants (i.e., frequency of lung cancer-related thoughts, degree to which lung cancer related thoughts affected mood and ability to perform daily activities, and degree of lung cancer concern).

Statistical Analysis

Because of the sample size of this pilot study, the quantitative assessments focused on visual representations of the data and on observations of trends. Frequencies and percentages were used to characterize the study population with regard to demographic and psychological variables. To gain power, psychological measures were collapsed (i.e., agree vs. disagree). All statistical analyses were performed using SAS (SAS Institute Inc., Cary, NC).

Results

Demographic and spiral CT findings

A total of 60 participants (29 male, 31 female) ≥ 30 years of age who had a first degree relative with lung cancer in a kindred containing at least three blood relatives with lung cancer underwent SCT screening. SCT screening detected negative results (clear lungs, no lesions detected) for 40 participants (67%); non-negative results (lesions detected) were detected for 19 participants (31%) warranting follow-up SCT between 6–12 months; and one participant (2%) was diagnosed as having lung cancer requiring immediate follow-up (Table 1). Among those participants who received a non-negative result 5 individuals had a 6 month SCT follow-up at Mayo Clinic, 5 individuals had a 12 month follow-up at Mayo Clinic, and 9 individuals had a follow-up CT at 6 or 12 months that was performed outside of Mayo.

Tobacco use

Overall, 57 (95%) of the respondents were ever smokers and 3 (5%) never smoked. Of the ever-smokers, 26 (43%) and 31 (52%) were current and former smokers, respectively (Table 1).

Expectations of accuracy of lung cancer screening results

At baseline, respondents were split on their opinion as to whether or not it is “OK if a test detects less than 100% of people who have lung cancer” (Table 2). On the other hand, when asked if it is “OK if a test says that cancer may be present when it is not,” a large majority (74%) disagreed with this statement.

Expectations of accuracy about lung cancer screening results were even higher when the questions were asked regarding their personal situation. For example, 84% disagreed with the statement, “If a test says I may have lung cancer when I do not that is OK with me,” and 92% disagreed with the statement, “If a test says I do NOT have lung cancer when I DO, that is OK with me.” By months 1 and 6, among those who received a negative SCT screening result, percent changes in all of the questions regarding expectations of accuracy about lung cancer screening were fairly small and expectations were very high regarding the accuracy of lung cancer screening results. Among those receiving non-negative results, the largest percent changes over time were reported both globally and personally with regard to a false-negative. The percent agreeing with the global statement, “OK if test says cancer may be present when it is not,” increased by 21% at 1 month and decreased by 1% at 6 months. The percent agreeing with the personal statement, “If a test says I may have lung cancer when I really do not” increased by 30% at 1 month with a final increase of only 4% at 6 months (Table 2).

Lung cancer risk perception

At baseline, a large majority of respondents reported higher levels of both absolute (64%) and comparative perceived cancer risk (76%). One month after receiving their SCT result, those with a non-negative result requiring follow-up reported higher levels of absolute risk (75%), and lower levels of comparative (69%) cancer risk compared to baseline. Those who received a negative result reported about the same level of absolute (63%) and comparative (74%) cancer risk compared to baseline. At 6 months post SCT, absolute perceived cancer risk approached baseline levels among those receiving negative results (66%). A change in estimates of perceived comparative cancer risk was detected in the negative results group. This group showed an increase from 17% (one month) to 40% (six months) in those who believed their risk of developing lung cancer was similar to others of the same age, sex, and race. Those who perceived their comparative cancer risk to be the same as others of same age, sex, and race and who received a non-negative result exhibited a short-term (one month) increase (16% to 25%), but this perception did not persist at 6 months, dropping to 13%. (Table 3).

Lung cancer worry/concern

At baseline, over half of respondents reported having some thoughts about getting lung cancer (65%), and a large majority of respondents reported being concerned about getting lung cancer (94%). Despite the high level of cancer-related thoughts and concerns, over half of respondents reported that thoughts about getting lung cancer did not affect their mood (66%), and a large majority reported that thoughts and concerns did not affect their ability to perform their daily activities (92%). Individuals who received a negative result reported a small decrease from baseline to follow-ups at 1 and 6 months in lung cancer-related thoughts (65%, 54%, 59%), mood (34, 29%, 21%), and concerns (94%, 89%, 91%).

Among those who received a non-negative result, the percentage reporting cancer related thoughts increased from 65% at baseline to 87% at one month, but dropped to 69% at six months. Reports of lung cancer related concerns also increased among those with a non-negative result at 1 month (100%) and decreased to baseline (94%) levels at 6 months. Despite the short-term increase in cancer related thoughts and concerns among this group of respondents, it did not correspondingly increase their mood (27% at 1 month and 31% at 6 months) nor daily activities (0% at 1 month and 6% at 6 months). (Table 3)

Discussion and Conclusion

This study explored perceptions of the accuracy of SCT screening among individuals in families having 3 or more first degree relatives with lung cancer. Adding a new level of insight, our results found that all participants expect lung cancer screening tests to be highly accurate, but especially in relation to non-negative results. Of particular interest, we found participants to be more tolerant of inaccuracy in lung cancer screening results when the question was worded generally, rather than personally or specific to their own circumstances. This methodological finding may be helpful to researchers who are attempting to develop more precise self-report measures of perceptions of screening accuracy. With regard to those receiving non-negative results, an increase in agreement was expressed resulting in about half being “OK” with a nonnegative at 1 month, but this tolerance for inaccuracy in screening results returned to baseline levels at 6 months. These findings suggest that efforts need to be made to ensure that individuals are aware of the limitations and pitfalls of new screening technologies and of the potential need for further follow-up in the context of a non-negative result. The need for individuals to understand the limitations of screening technology has also been underscored recently by the American Cancer Society, who have publicized even recommended population level screening technologies have the potential to miss cancerous tumors or to identify tumors that would not necessarily result in a cancer but necessitate unnecessary medical procedures (3).

We also assessed how this screening experience affected risk perception and cancer-related concern. A large percentage of respondents reported high levels of perceived lung cancer risk and lung cancer-related worry/concern, regardless of screening results at all time points. Because overestimation of personal lung cancer risk and cancer related worry/concern are reported among individuals with a family history of cancer (15,24,30), there is a need to develop new methods and strategies for imparting risk information to patients.

Our results indicated a difference in reporting of perceived absolute and comparative cancer risk among individuals who received negative and non-negative results. At one month post SCT, a higher proportion of those receiving a negative result reported having a higher risk compared to others of their same age, race vs. those who received a non-negative result. At the same time, levels of perceived absolute risk stayed virtually the same among those receiving a negative result, while increasing substantially among those receiving non-negative results. These findings suggest that both perceived absolute and comparative risk are overestimated at all time points, but that the result, or the interaction with the physician conveying results, is serving to make an adjustment in comparative cancer risk perception, though not in absolute risk perception.

The most dramatic changes in reports of perceived risk and worry/concern were reported at 1-month post SCT, especially with regard to the degree of thoughts about getting lung cancer among those receiving a non-negative SCT result. However, changes in perceived risk and cancer worry/concern returned almost to baseline levels at 6 months post SCT, which is similar to findings by Byrne et al. (15) and Vierikko et al. (26). Thus, short-term psychosocial impacts of screening do not appear to persist over time. It would be interesting to determine whether this elevated perceived risk is related more to family history or to the fact that the majority of respondents had a smoking history, though were not current smokers. Future large-scale studies could determine whether family history, smoking, or a combination of the two contributed to these high levels of perceived risk. These findings also suggest that the timing of interventions designed to address issues related to perceived risk and worry and concern should take place immediately after individuals receive their screening results.

Due to our small sample size, we recognize that the results of this study must be interpreted with caution and viewed as preliminary. We collapsed response categories of standard questions and the sample size precluded univariate or multivariate analyses. We did not have a comparison group to determine whether this sample's perception of risk and cancer-related worry/concern differs from the general population. In addition our sample was composed of participants from 24 families and interrelatedness of respondents was not accounted for in our analyses. Despite the limitations of this pilot study, our findings have provided insight into participants' expectation of accuracy about lung cancer screening results and suggest ways to improve understanding of SCT screening and to better align perceived and actual risks.

Conclusion

All participants in this study reported high levels of expectations of test accuracy, perceived lung cancer risk and lung cancer-related thoughts and concerns. The results of this study can help investigators develop studies to better understand and ultimately address the educational and support needs of individuals undergoing SCT screening when they are most vulnerable. These findings could be applicable to other types of screening with proven efficacy as well.

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Table 1

Baseline characteristics of participants in high familial risk spiral CT screening study (N=60)

	Male (n=29) N (%)	Female (n=31) N (%)	Total (n=60) N (%)
Age (mean, SD)	53.3 (11.0)	51.7 (11.1)	52.5 (11.0)
Race-Ethnicity			
Caucasian	29 (100%)	29 (93%)	58 (97%)
Unreported	0 (0%)	2 (7%)	2 (3%)
Number of first degree relatives (FDRs) with lung cancer			
1	18 (62%)	22 (71%)	40 (67%)
2	4 (14%)	5 (16%)	9 (15%)
3	7 (24%)	4 (13%)	11(18%)
Spiral CT Screening Results*			
Negative	20 (69%)	20 (65%)	40 (67%)
Non-Negative	8 (28%)	11 (35%)	19 (31%)
Lung Cancer	1 (3%)	0 (0%)	1 (2%)
Smoking Status			
Never	1 (3%)	2 (7%)	3 (5%)
Former	17 (59%)	29 (45%)	31 (52%)
Current	11(38%)	15 (48%)	26 (43%)

* Negative = clear lungs, no lesions detected; Non-negative = lesions detected warranting 3–6 month follow-up visit

Table 2

Expectations for accuracy of screening results at baseline and by spiral CT screening result at 1 and 6 months

Question	Baseline (n, %)		1 month (n, %)		6 month (n, %)	
	negative	non-negative	negative	non-negative	negative	non-negative
It would be OK if a test detects less than 100% of people who have lung cancer.						
Agree (1)	25 (52%)	16 (50%)	7 (50%)	15 (44%)	5 (31%)	11 (69%)
Disagree (2)	23 (48%)	16 (50%)	7 (50%)	19 (56%)	11 (69%)	11 (69%)
It would be OK if a test says cancer may be present in a person who really does not have lung cancer.						
Agree (1)	13 (26%)	7 (21%)	7 (47%)	5 (15%)	4 (25%)	12 (75%)
Disagree (2)	37 (74%)	26 (79%)	8 (53%)	29 (85%)	12 (75%)	12 (75%)
If a test says I may have lung cancer when I do not have that is OK with me.						
Agree (1)	8 (16%)	6 (18%)	6 (46%)	4 (12%)	3 (20%)	12 (80%)
Disagree (2)	41 (84%)	27 (82%)	7 (54%)	29 (88%)	12 (80%)	12 (80%)
If a test says I do NOT have lung cancer when I DO, that is OK with me.						
Agree (1)	4 (8%)	5 (15%)	3 (20%)	4 (12%)	1 (6%)	15 (94%)
Disagree (2)	47 (92%)	28 (85%)	12 (80%)	29 (88%)	15 (94%)	15 (94%)

* Negative = At baseline, clear lungs, no lesions detected; Non-negative = At baseline, lesions detected warranting follow-up

Psychosocial measures of participants from high risk families at baseline and by screening result at 1 and 6 months post spiral CT lung cancer screening

Table 3

Question	Baseline (N, %)	1 month (N, %)		6 month (N, %)	
Spiral CT result*		Negative	Non-negative	Negative	Non-negative
Cancer thoughts					
Not at all	18 (35%)	16 (46%)	2 (13%)	14 (41%)	5 (31%)
Some	33 (65%)	19 (54%)	13 (87%)	20 (59%)	11 (69%)
Mood affected					
Not at all	33 (66%)	25 (71%)	11 (73%)	27 (79%)	11 (69%)
Some	17 (34%)	10 (29%)	4 (27%)	7 (21%)	5 (31%)
Daily activity affected					
Not at all	46 (92%)	34 (97%)	15 (100%)	32 (94%)	15 (94%)
Some	4 (8%)	1 (3%)	0 (0%)	2 (6%)	1 (6%)
Cancer concern					
No concern	3 (6%)	4 (11%)	0 (0%)	3 (9%)	1 (6%)
Concern	47 (94%)	31 (89%)	15 (100%)	31 (91%)	15 (94%)
Perceived comparative cancer risk					
Higher	38 (76%)	26 (74%)	11 (69%)	20 (57%)	13 (81%)
Same	8 (16%)	6 (17%)	4 (25%)	14 (40%)	2 (13%)
Lower	4 (8%)	3 (9%)	1 (6%)	1 (3%)	1 (6%)
Perceived absolute cancer risk					
Likely	32 (64%)	22 (63%)	12 (75%)	23 (66%)	12 (75%)
Neither likely nor unlikely	4 (8%)	5 (14%)	1 (6%)	3 (9%)	1 (6%)
Unlikely	14 (28%)	8 (23%)	3 (19%)	9 (25%)	3 (19%)

* Negative = At baseline, clear lungs, no lesions detected; Non-negative = At baseline, lesions detected warranting follow-up