Aiding shared decision making in lung cancer screening: two decision tools

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ABSTRACT

Background Shared decision making (SDM) preceding lung cancer screening is important for populations that are underrepresented in lung cancer screening trials. Current evidence-based guidelines; however, do not address personal risk and outcomes in underrepresented populations. This study compared two SDM decision aids (Option Grids and [Shouldiscreen.com](https://www.shouldiscreen.com)) for SDM efficacy, decision regret and knowledge.

Methods We conducted a prospective trial of lung cancer screening patients ($N = 237$) randomized to SDM with Option Grids or [Shouldiscreen.com](https://www.shouldiscreen.com). To evaluate the SDM process after lung cancer screening, patients answered two questionnaires: CollaboRATE and Decision Regret. Patients also completed a questionnaire to test their knowledge of lung cancer screening.

Results Patients were predominantly African American (61.6%), though multiple races, varying education levels and equal genders were represented. Patients in both Option Grids and [Shouldiscreen.com](https://www.shouldiscreen.com) groups reported favorable SDM experiences ($P = 0.60$) and equivalent knowledge about lung cancer screening ($P = 0.43$). Patients using [Shouldiscreen.com](https://www.shouldiscreen.com) had less knowledge regarding the potential complications of subsequent testing ($P = 0.02$). [Shouldiscreen.com](https://www.shouldiscreen.com) patients had increased regret regarding their decision to pursue screening ($P = 0.02$).

Conclusions Option Grids and [Shouldiscreen.com](https://www.shouldiscreen.com) both facilitated a meaningful SDM process. However, Option Grids patients experienced decreased decision regret and enhanced knowledge of the potential complications of screening.

Keywords lung cancer screening, patient knowledge, shared decision making,

Introduction

In 2011, results from the National Lung Screening Trial (NLST)^{1,2,3,4,5} demonstrated a 20% reduction in lung cancer mortality with the use of low-dose computed tomography (LDCT).⁵ The results, however, could not be extrapolated to all populations, since 90% of participants were Caucasian, a majority were male, and 68.7% had training or education beyond high school.⁶ Furthermore, the potential benefit of screening has been found to vary by several orders of magnitude across participants.⁷ As a result, current evidence regarding lung cancer screening may not be applicable to all patients who meet eligibility criteria, particularly those in minority or underserved populations.

Communication of personalized lung cancer risk and the potential risks and benefits to individual patients requires

shared decision making (SDM). SDM is a process whereby a patient and a healthcare provider arrive at a care plan that is best suited for the individual patient based on current evidence and patient values.³ SDM in the context of lung cancer screening includes a discussion about the potential benefit of decreasing the risk of dying from lung cancer, as well as the potential harms, including false positive results, complications as a result of positive screens, over diagnosis

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and radiation exposure.⁸ An SDM experience should also include a discussion about the importance of follow-up care after screening and the importance of smoking cessation.⁹ Numerous studies assert that SDM is essential to successful lung cancer screening.^{10–13} Several professional societies, including the US Preventive Services Task Force Services and the Centers for Medicaid and Medicare (CMS), have established guidelines for implementing SDM with the use of SDM aids in lung cancer screening protocols.^{14–18} Decision aids are tools that facilitate SDM by prompting meaningful discussions between patients and healthcare providers. However, to date, evidence regarding the utility and effectiveness of SDM and SDM decision aids in the setting of lung cancer screening is lacking.

SDM is particularly important when implementing lung cancer screening in diverse populations. Because of the current disparity of evidence for lung cancer screening in minority populations, each patient should have a personalized discussion about risk of lung cancer and potential benefits and harms of screening. Previous research suggests that SDM could play a crucial role in enhancing the healthcare experience and outcome among the medically underserved populations.^{19–21} SDM methods that emphasize information sharing, open discussion and establishing patient-provider trust could increase adherence to lung cancer screening guidelines and treatment.^{19–21}

With limited data on the best approach to SDM, we designed a randomized, prospective trial comparing two widely available decision aids, namely Options Grids and Shouldiscreen.com. The aids were assessed to determine their efficacy, the amount of knowledge they impart to patients, and the degree to which they are associated with decision regret regarding the patient's choice to pursue lung cancer screening. Option grids present specific evidence about the potential risks, benefits and alternatives to lung cancer screening using a 'Frequently Asked Questions' format.^{22, 23} Shouldiscreen.com is an online decision aid that includes current evidence about lung cancer screening, as well as a personalized risk assessment calculator.^{24, 25} We conducted this study in an underserved, predominantly African American population, underrepresented in previous lung cancer screening trials.

Methods and materials

All protocols and procedures received approval by the Temple University Health System Institutional Review Board (Committee A1; Approval #23095). Between August 2015 and January 2017, we conducted a prospective, randomized study of patients undergoing lung cancer screening in an urban,

academic medical center. Patients referred by physicians called Temple University Hospital's lung cancer screening program to arrange for a visit. Prior to the screening visit, a nurse confirmed eligibility for lung cancer screening with the patient by a phone call. For eligible patients, this same nurse arranged for a single visit consisting of an SDM visit, LDCT scan and follow-up visit on the same day. Patients who attended their lung cancer screening appointment were screened for eligibility for this study. The inclusion criteria utilized were: (i) age between 55 and 80, (ii) smoking history of at least 30 pack-years, (iii) actively smoking or quit smoking within the past 15 years, (iv) reliable communication by mail and telephone, (v) at least a sixth-grade reading level, as assessed by the Rapid Estimate of Adult Literacy in Medicine criteria, (vi) fluency in English and (vii) not cognitively impaired.²⁶ The exclusion criteria were: (i) symptoms suggestive of lung cancer, such as hemoptysis or unexplained weight loss, (ii) previous lung cancer, (iii) previous cancer of any origin with active treatment within the past 5 years or (iv) any comorbidity or condition that precluded them from lung cancer treatment. In total, 237 patients participated in this study.

Study design

In a large, urban, academic health system, we developed a lung cancer screening program that incorporates an SDM visit, LDCT scan and discussion of results within a single-day visit.²⁷ Eligible patients consenting to participate in our study were randomized with a web-based randomization tool to receive either a directed SDM discussion utilizing Option Grids, found at www.optiongrid.org, or the online decision aid, www.shouldiscreen.com.^{23, 24} Option Grids is a brief information sheet to guide a physician-patient encounter in which patients and providers can select compare lung cancer screening options and made a decision. Shouldiscreen.com included a web-based calculator consisting of 12 questions to calculate the risks of lung cancer. The results will indicate how much a person stands to benefit from getting screened, and help the person better determine whether their potential benefit from screening outweighs the harms.

After randomization, demographic information was collected. All patients participated in an SDM visit with a physician specializing in lung cancer screening within the Temple University Department of Thoracic Medicine and Surgery. Patients randomized to use Option Grids were asked to review the questions and answers posed on the one-page decision tool. The provider asked each patient to circle at least one question that was most important to him or her. The provider and the patient then discussed all the questions asked by the patient. Patients randomized to use Shouldiscreen.com

Fig. 1 Flowchart of study design.

were asked to answer questions for the risk calculator and received their personalized risk. The physician navigated the patient through the website. Patients of both cohorts had an opportunity for further discussion with a physician prior to deciding if they would pursue screening.

The study design can be found in Fig. 1. The 237 patients who decided to proceed with lung cancer screening received their LDCT scan immediately following their SDM visit and returned to the lung cancer screening physician for the results of the LDCT. Results of the LDCT were reported using the standardized reporting system, LungRADS. After receiving the results of lung cancer screening, patients answered two questionnaires: 209 patients completed the CollaboRATE, and 179 patients completed the Decision Regret. About 3–6 months following the SDM experience, 87 patients completed the Knowledge Questionnaire by telephone.

Questionnaires administered

The knowledge retention questionnaire was a 14-question questionnaire about lung cancer screening. This questionnaire

was assembled using a revised version of the Lau *et al.* knowledge questionnaire,²¹ in addition to questions we felt were important for knowledge retention. A difference of 15% points was considered significant based on past studies evaluating knowledge retention in SDM.^{30, 31} With a type I error rate of 0.05, a power of 90% and a null hypothesis that knowledge retention would be statistically insignificant between the two groups, a sample size of 32 was necessary to detect a difference of 10% points. Effectiveness of the SDM experience was measured with CollaboRATE, a validated patient-reported measurement of SDM.²⁸ CollaboRATE is a three-item measure of the SDM process. Items included are, ‘How much effort was made to help you understand your health issues?’ ‘How much effort was made to listen to the things that matter most to you about your health issues?’ and ‘How much effort was made to include what matters most to you in choosing what to do next?’ The CollaboRATE survey achieves 80% power and 95% confidence to detect a minimum detectable difference of 7.6 in outcome given standard deviations of 19.1 in each group.²⁹ The Ottawa

Decision Regret Scale was used to measure the consequence of SDM with a five-item questionnaire.

Decision regret was measured utilizing the validated Ottawa Decision Regret Scale.³⁰ Both tools were used to measure patients' perception of the SDM process that occurred with the physician. The Knowledge Questionnaire was a 14-question survey based on the Lau *et al.* knowledge questionnaire.²⁵ A difference of 15% points was considered significant based on past related studies.^{31, 32} The questionnaires used can be found in Appendices 1–3.

Statistical and qualitative analyses

Two sample *t*-tests and Mann–Whitney *U* tests were utilized for statistical analyses for samples comparing independent variables based on sample size. Chi-squared analyses were used to compare categorical data and an Analysis of Covariance testing was used to test the effect of categorical variables with continuous variables while controlling for additional confounders. Regression analysis was used to compare mean knowledge between patients who used Option Grids versus [Shouldiscreen.com](#) while controlling for education level. All statistical analyses were performed using the statistical software Stata 15.³³

Results

Baseline characteristics

From 2015 to 2017, 237 patients were randomized to receive SDM with Option Grids (*n* = 128) or [Shouldiscreen.com](#) (*n* = 109). The baseline characteristics of these patients were equivalent in terms of race (*P* = 0.15), age (*P* = 0.44), gender (*P* = 0.20), pack-year (*P* = 0.36), level of education (*P* = 0.39) and LungRADS category (*P* = 0.43) (Table 1). The patient population was 146 (61.6%) African American, 69 (29.1%) Caucasian, 17 (7.2%) Hispanic and 3 (1.3%) Asian/Pacific Islander. There were 115 (48.5%) men and 122 (51.5%) women. LungRADS results were 3 (1.5%) LungRADS 0, 92 (46.2%) LungRADS 1, 85 (42.7%) LungRADS 2, 8 (4.0%) LungRADS 3, 9 (4.5%) LungRADS 4a, 1 (0.5%) LungRADS 4B and 1 (0.5%) LungRADS 4X.

Questionnaires

Patients in both randomized groups completed a CollaboRATE questionnaire after their screening to discuss the efficacy of SDM and their experience with the SDM process that just occurred with the physician (Fig. 2). The mean score for Option Grids participants was 97.4% and the mean score for [Shouldiscreen.com](#) patients was 98.6% (*P* = 0.60). Patients using Option Grids had significantly less decision

Table 1 Descriptive statistics of the study sample, 2015–2017

Demographics	Option grids	Shouldiscreen.com	P-value
Race (<i>n</i>)			0.15
African American	71	75	
Caucasian	46	23	
Hispanic	8	9	
Asian/Pacific Islander	2	1	
Unknown	1	1	
Mean age	64	64	0.44
Gender (<i>n</i>)			
Male	57	58	0.20
Female	71	51	
Median duration of PY	42	44	0.36
Level of education (<i>n</i>)			0.39
<Ninth grade graduated	6	7	
9th–11th grade graduated	30	35	
High school degree/GED	46	35	
Associates degree	8	11	
Some bachelor's degree	20	10	
Bachelor's degree	9	3	
Graduate degree	4	4	
Lung-RADS (<i>n</i>)			0.43*
0	0	3	
1	50	42	
2	48	37	
3	5	3	
4	4	5	

**P*-value for exploratory purposes only given imbalance of LungRADS categories.

regret (mean decision regret; 6.0 with Option Grids versus 10.2 with [Shouldiscreen.com](#); *P* = 0.0198) and significantly more knowledge regarding the work-up of positive screens, including the possible need for invasive procedures (84.8% understood correctly with Option Grids versus 63.4% understood correctly with [Shouldiscreen.com](#); *P* = 0.02).

In terms of decision regret associated with choosing to proceed with the LDCT scan, patients who utilized Option Grids had significantly less regret compared to patients who used [Shouldiscreen.com](#) (mean decision regret score 6.0 versus 10.2; *P* = 0.0198) (Fig. 3). Further analysis revealed no correlation between increased LungRADS score and increased decision regret (*P* = 0.67) or lower CollaboRATE score (*P* = 0.08).

The patients' overall knowledge was equivalent, with a mean correct score of 64.7% with Option Grids and 62.4% with [Shouldiscreen.com](#) (*P* = 0.43) (Fig. 2). The questions of the Knowledge Questionnaire were individually analyzed

Fig. 2 Average CollaboRATE scores, Knowledge Score and Ottawa Decision Regret Score in patients after shared decision making using Option Grids versus ShouldIscreen.com.

Fig. 3 Average statistical significance when comparing themes of questions answered in Knowledge Questionnaire between patients using Option Grids versus ShouldIscreen.com. *Indicates statistical significance.

to determine if there were specific topics of lung cancer screening risk factors, benefits, harms and follow-up testing that differed between groups. The only statistically significant difference was knowledge about potential complications from the work-up of a positive LDCT scan (Option Grids versus ShouldIscreen.com; 84.8% correct versus 63.4% correct; $P = 0.02$) (Fig. 3).

Regression analysis was used to compare mean knowledge between patients using Option Grids versus ShouldIscreen.com while controlling for education level. This analysis revealed no correlation between education level and knowledge retention in patients who used Option Grids ($r = 0.09$; $P = 0.61$) or ShouldIscreen.com ($r = 0.01$; $P = 0.95$).

Discussion

What is already known on this topic

The incidence of lung cancer in the USA is ~222 500 per year, with mortality about 155 870 individuals annually.³⁴ LDCT scan to screen for lung cancer has the potential to avert 12 000 deaths annually through early detection of cancer and successful treatment.³⁵ However, because participants of the NLST were largely Caucasian, healthy and educated, the generalizability of NLST results across patient populations is unknown.⁵ Even within the NLST population, the calculable risk of dying of lung cancer varied by more than 10-fold.³⁶ Therefore, clinicians should engage eligible patients in an SDM discussion.

SDM promotes understanding of lung cancer screening¹¹ and encourages individuals to make healthcare decisions about lung cancer screening that are consistent with their preferences and values.³⁷ Several professional societies have advocated for SDM, and CMS has implemented a mechanism for reimbursement for an SDM visit prior to lung cancer screening. These guidelines include the use of a decision aid to facilitate a personalized discussion about potential benefits and harms of screening and the possibility of follow-up diagnostic testing or treatment.¹⁸ However, to date, there is little evidence on which decision aids effectively facilitate SDM.

What this study adds

Our study examines the efficacy of SDM, decision regret and lung cancer-specific knowledge using two decision aids, Option Grids and ShouldIscreen.com. We conducted the study in a minority population with a diversity of educational

backgrounds. SDM is especially important for minority groups, who have been underrepresented in most lung cancer screening trials, to discuss how existing evidence relates to individuals in minority populations. Because personalized discussions between healthcare providers and individual patients have shown to result in improved SDM experience,¹⁰ we looked to study quantifiable measures of SDM using validated instruments, namely CollaboRATE and Ottawa Decision Regret Scale and lung cancer-specific knowledge test. We hypothesized that Option Grids would result in enhanced SDM, since it is designed to prompt a personalized dialog between the provider and the patient.

Main findings of this study

In a diverse, but predominantly African American population of 237 patients undergoing SDM with lung cancer screening, we demonstrated that patients utilizing either Option Grids or [Shouldiscreen.com](#) had a favorable SDM experience, as demonstrated by high CollaboRATE scores, low decision regret and comparable knowledge about lung cancer screening after 3–6 months. In addition, neither the patients' level of education nor LDCT results influenced questionnaire scores. Thus, use of Option Grids or [Shouldiscreen.com](#) as a decision aid prior to lung cancer screening results in favorable, patient-reported SDM experiences.

Though both Option Grids and [Shouldiscreen.com](#) facilitate a meaningful patient-reported SDM experience, each decision aid has advantages and disadvantages. Option grids encourage a discussion between the patient and provider by requiring the patient to choose topics to discuss. However, Option Grids must be administered by providers willing to discuss the topics. Use of Option Grids requires minimal resources and training, which can be accessed at [Option.Grids.com](#).²³ All evidence conferred in Option Grids includes references for providers to use if needed.²² Option Grids highlight information about follow-up care, which may be the reason for enhanced knowledge regarding potential harms of lung cancer screening compared to [Shouldiscreen.com](#). Since Option Grids is in printed form, there may be a misperception or temptation to simply hand the decision aid to the patient without discussing the content. Another potential disadvantage of Option Grids is the requirement for patients to have a fourth-grade reading level in English, which may limit its use. Overall, Option Grids provided favorable patient-reported SDM, low decision regret and high levels of knowledge about lung cancer screening.

Like Option Grids, [Shouldiscreen.com](#) provided favorable patient-reported SDM experience. [Shouldiscreen.com](#) is a user-friendly SDM aid that is available online. [Shouldiscreen.com](#)

also has a personalized lung cancer risk calculator.²⁴ In our study, clinicians and patients navigated through the [Shouldiscreen.com](#) website together. A disadvantage of [Shouldiscreen.com](#) is the need for access to a computer and internet access during the SDM visit. Another potential disadvantage of [Shouldiscreen.com](#) is the possibility of providers navigating patients through the website without prompting a personalized discussion. Similar to Option Grids, providers must be willing to engage in a meaningful discussion about lung cancer screening.

Limitations of this study

The study has limitations. First, our study compared efficacy of SDM and knowledge about lung cancer screening in the short term. It is possible that patients have evolving impressions of SDM and knowledge over time. Patients may experience anxiety, need for follow-up studies, or even complications that may influence their long-term satisfaction with SDM. Further study into long-term effects of each SDM aid is currently underway. Second, it is unknown how our results compare to patients who did not use a decision aid. We did not include such a control group in our study because it would be contrary to current screening guidelines. Third, only 63% patients completed questionnaires in short-term follow-up of 3–6 months. This might have introduced bias into the results, with participating patients more likely to be satisfied with their experience. In addition, we did not study the change in knowledge from before and after our SDM visit. We only compared knowledge between the two cohorts, not knowledge gained at the SDM appointment. Future study will measure baseline knowledge of patients, as well as knowledge after an SDM visit. Fourth, it is unknown how adherent healthcare providers are to the recommendation for use of a decision aid. Further study of implementation and efficacy of decision aids is needed. Finally, ours is a pilot study within a single institution with a volume of 237 patients. Further study of the time, resources, and cost-effectiveness of each decision aid will be necessary.

Conclusion

In a prospective, randomized trial looking at the use of Option Grids and [Shouldiscreen.com](#) as decision aids for SDM prior to lung cancer screening, both aids were found to confer favorable patient-reported SDM experience, low decision regret and lung cancer screening-specific knowledge. However, patients using Option Grids had less decision regret and increased knowledge about follow-up care compared to patients using [Shouldiscreen.com](#).

Supplementary data

Supplementary data are available at the *Journal of Public Health* online.

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