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Development of Decisional Values Statements for Lung Cancer Screening Among African American Smokers

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Abstract

Lung cancer screening via low-dose computed tomography (LDCT) has been underutilized by high-risk current and former smokers since its approval in 2013. Further, lower use of other evidence-based cancer screening tests (e.g., colorectal cancer, breast cancer) has been noted among African Americans when compared with other racial and ethnic groups. Reasons for low uptake are multilayered but include the need for consideration of patients' personal values about the screening decision. The goal of the present study was to (1) identify positive and negative factors specific to lung cancer screening via LDCT and (2) develop statements to capture values about the screening test for use in a new measure of decisional values. Key informant interviews ($n = 9$) identified several benefits and risks of lung cancer screening that may be important to African American smokers. Based on these interviews, a pool of items with the values statements was administered to a convenience sample of 119 African Americans [aged 55–80 years, current or former smokers (who quit <15 years), and without lung cancer]. An exploratory factor analysis revealed two components explaining 64% of the variance: *cons of screening* (e.g., “make you feel badly about your smoking history”) and *pros of screening* (e.g., “lowering your risk of dying from lung cancer”). The final 12-item measure had very good internal consistency ($\alpha = 0.89$ overall; $\alpha = 0.86$ and 0.88 for subscales, respectively). This tool provides a promising values measure for lung cancer screening among African Americans and could inform future values clarification tools promoting informed and shared decision-making.

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Conflict of Interest The authors declare that they have no conflicts of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committees (University of Maryland Institutional Review Board (#1300307-1)) and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Statement of Informed Consent Informed consent was obtained from all participants included in the study. This work was approved by the University of Maryland Institutional Review Board (#1300307-1).

Keywords

Lung cancer screening; Low-dose computed tomography; Informed decision-making; Decisional values; African Americans

Introduction

Results from the National Lung Screening Trial (NLST) found a 20% relative reduction in lung cancer mortality in participants who received lung cancer screening using low-dose computed tomography (LDCT) versus radiography [1]. The findings from this trial guided the US Preventive Services Task Force (USPSTF) to release a grade B recommendation for annual lung cancer screening for individuals who are considered high risk – i.e., 55 to 80 years old, 30-pack-year smoking history, and who currently smoke or who have quit in the last 15 years [2]. LDCT utilization is low overall, and one recent study reported that African American participants had lower intentions to be screened in comparison to their White counterparts [3]. The burden of lung cancer is significant, especially African American men, who have the highest lung cancer death rates compared to all other racial and ethnic groups [4].

While there are clear benefits of LDCT screening (i.e., mortality reduction), there are also limitations (e.g., falsepositive results) and risks (e.g., radiation exposure) associated with the test [1]. Given these considerations, providers and patients must collectively engage in shared decision-making (SDM) by weighing the benefits, limitations, and harms [5]. Individuals eligible for lung cancer screening are encouraged to consider their personal preferences and to make a decision that is aligned with their own values. Values in this context refer to the “desirability or personal importance a respondent places on the benefits and risks of an option” [6]. For example, in another preference sensitive medical decision, respondents are asked to consider factors (e.g., “I am worried about prostate cancer and screening may give me peace of mind”, “I do not want to risk finding out I have prostate cancer when it may never bother me”) that are viewed as important by people deciding about prostate cancer screening and then asked to indicate how important each factor is to them [7].

Although current research is addressing personal values in lung cancer screening through the inclusion of values clarification exercises in decision aids [8–13], it is acknowledged that factors influencing patient behavior may be specific to the screening modality [14, 15]. The Ottawa Decision Support Framework posits that values and preferences may be specific to the *type of decision* to be made as well as the *characteristics of those involved in making the decision* [6]. There are also differences between groups regarding their willingness to engage in the process of informed and shared decision-making, their interest in playing an active role in health decisions, as well as their ability to understand the complex nature of decision-making [16]. Elucidating factors that are specific to individuals facing the lung cancer screening decision, as well as exploring the role of background characteristics, can help inform future values clarification exercise statements used to make an informed decision or during a SDM encounter. The goal of the present study was to (1) identify positive and

negative factors specific to lung cancer screening via LDCT and (2) develop statements to capture values about the screening test for use in a new measure of decisional values. In this paper, we describe findings from key informant interviews ($n = 9$) that informed the development of the values statements and present the psychometric properties of the decisional values tool that was administered to African Americans smokers ($n = 119$).

Methods

Key Informant Interviews

We conducted key informant interviews at the provider and patient level to obtain information about decisional values that may be salient to African American smokers when considering lung cancer screening. Providers were recruited using a purposive sampling method and included snowball sampling [17]. We contacted providers who were part of the lung cancer screening program at their respective institutions to request a 20-min phone interview. Verbal informed consent from all eligible and interested providers was obtained. Patients were invited to participate via flyers and by word of mouth. The criteria for inclusion were 55 to 80 years old, self-identified as African American, current or former smokers, and no history of lung cancer. A minimum pack-year history was not an inclusion criterion due to the lower likelihood of 30 + pack-years among African American smokers [18]. The patient participants provided informed consent, completed the interview, and received \$10 as a thank-you for their time. All interviews were digitally recorded and transcribed verbatim using an external transcription service. This research was approved by the Institutional Review Board (#1300307-1).

The semi-structured interview guide consisted of items based upon the type of interviewee – provider or patient. For example, we asked providers: “I would like you to think about why patients may [or may not] get tested for lung cancer using low-dose computed tomography. Please tell me all the possible reasons you can think of and explain why patients [do or do not] get screened.” Patients were asked, “I would like you to think about why you might [or might not] get tested for lung cancer using low-dose computed tomography. Please tell me all the possible reasons you can think of and explain why you might [or might not] get tested.”

Provider and Patient Characteristics

Providers ($n = 5$) included a primary care physician, oncologist, thoracic surgeon, pulmonologist, and radiologist representing four different healthcare institutions located in Miami, Baltimore, and Chapel Hill (North Carolina). Providers' race/ethnicity was not captured. The patients ($n = 4$) were African American and included two males and two females ($M = 69$ years, $M = 11.5$ cigarettes per day). Two currently smoked and two were former smokers. The interviews were conducted in September and October 2018, and the data collection period ended once no new response themes were emerging from the conversations; thematic saturation was reached [19].

Survey Item Generation

Each interview was transcribed verbatim and compared to its recording for accuracy by the first author. Next, a content analysis of the data was conducted to identify themes and categories. The first author reviewed the transcripts, providing labels (positive factors, negative factors) to the relevant text. These statements were grouped into categories (mortality benefit, psychological effects, interpersonal relationships, burden of test itself, hierarchy of life priorities, fear/fatalism, limitations of screening, stigma) that informed the development of the decisional values items for lung cancer screening (Table 1). Two senior authors reviewed the labels, categories, and draft items and made recommendations for refinement. The process was iterative in nature and items were revised until consensus was reached. The instructions and phrasing of the items were adapted from a validated decisional values scale and other values items used in the literature [16]. The 17-item self-administered measure includes statements framed in the context of the pros of getting screened for lung cancer and the cons of getting screened with the following stem: “Below are listed some things that people consider when making a decision about lung cancer screening using low-dose computed tomography. Please indicate how important these are to you by selecting ‘extremely important to me’ to ‘not at all important to me.’” Sample items include “How important is lowering your risk of dying from lung cancer?” (pro) and “How important is the idea that getting screened for lung cancer would make you feel badly about your smoking history?” (con). Individuals responded to the statements using a 5-point Likert-type scale (1 = not at all important to 5 = extremely important).

Cross-Sectional Study Survey Method

A multipronged approach was utilized for recruitment (e.g., advertisements in a local newspaper, speaking at five District of Columbia Housing Authority public housing communities). The eligibility criteria and incentives mirrored the patient key informant interview study. The survey took approximately 20 min to complete and included the 17-item decisional values measure as well as other items (e.g., LDCT knowledge and awareness, decisional uncertainty). To be inclusive of individuals at high risk and who may be eligible for screening according to the National Comprehensive Cancer Center guidelines (group 2), we asked participants with a 20 +-pack-year smoking history a single item to measure intention to be screened in the future.

Data analysis was conducted using SPSS 23.0. Descriptive statistics were computed to examine the distribution of the variables of interest (Table 2). The factor analysis included the full study sample ($n = 119$) to have an acceptable number of cases to the number of items. The factorability of the data was verified using the Kaiser-Meyer-Olkin Measure of Sampling Adequacy and Bartlett’s Test of Sphericity. An exploratory factor analysis was conducted to identify potential subscales. Internal consistency reliability (Cronbach’s alpha) was computed for the overall scale and subscales. Correlations were conducted between the subscales, and predictive validity was assessed by analyzing associations between the decisional values items and the lung cancer screening intention variable. Analysis of variance tests examined whether the decisional values items distinguished between smoking-related subgroups.

Results

Participant Characteristics

Table 2 provides the characteristics of the 119 participants who completed the survey (65% in person, 19% online, 16% phone). They were a mean age of 62.7 (SD = 6.3), 37.1% had some college or more, 26.7% were retired, most (74.8%) had an annual income of \$20,000 or less, and 85% went to their primary care physician for routine medical care. Regarding smoking status, 79% of participants currently smoked and 53.8% had a 20-pack-year smoking history. Respondents rated the pros of screening as high ($M = 22.1/25$, $SD = 3.8$), and the mean cons score was $M = 28.4/35$, $SD = 6.1$.

Item Characteristics

Prior to testing the 17-item measure for factorability, the Kaiser-Meyer-Olkin Measure of Sampling Adequacy and Bartlett's Test of Sphericity were conducted to determine how well suited the measure was for a factor analysis. Next, an exploratory factor analysis using the principal component analysis extraction method was conducted to determine any underlying factors. Eigenvalues greater than 1.0 and the scree plot were used to determine factor retention. The oblique rotation method was utilized, and, among the factors included in the pattern matrix, only those with a correlation coefficient > 0.40 and without cross-loading above 0.40 were included in the final model.

The initial model included three factors explaining 44%, 13%, and 7% of the variance, respectively. Factors were operationalized as the pros of screening, the cons of screening, and emotions related to the decision (e.g., "the feeling that if you had lung cancer you would feel like it was your fault," "getting screened for lung cancer would make you feel badly about your smoking history"). However, this initial model was not retained, because two of the three items in the third factor cross-loaded (> 0.40). After removal of ambiguous items and examination of the scree plot that revealed a leveling off after the second factor, the most parsimonious final two-factor model explained 64% of the variance (factor 1, 49%; factor 2, 15% proportion explained). The two-factor model included (1) *Cons of Lung Cancer Screening* (seven items, e.g., "lung cancer screening will not find all lung cancers or all lung cancers early,") and (2) *Pros of Lung Cancer Screening* (five items, e.g., "lowering your risk of dying from lung cancer," and "getting peace of mind"). The instrument had very good internal consistency reliability for the 12 items ($\alpha = 0.89$) and for the subscales ($\alpha = 0.86$ and 0.88, respectively). Table 3 presents the factor loadings for the final 12-item decisional values measure for lung cancer screening and includes the items dropped from the measure as a footnote in the table. The items for each subscale were summed, and the mean score for the *cons of screening* subscale was 28.4 (SD = 6.1) out of 35, and the *pros of screening* mean score was 22.1 (SD = 3.8) out of 25. A moderate significant positive correlation was detected between the subscales ($r = 0.558$, $p < 0.01$). Individuals who smoked a median of 35 + years reported lower ratings on the *cons of screening* ($M = 26.9$, $SD = 6.9$) in comparison to individuals who smoked for < 35 years ($M = 29.9$, $SD = 4.8$; $F(1, 108) = 6.5$, $p < 0.05$), indicating that longer-term smokers were less negatively inclined toward screening than shorter-term smokers.

To determine whether the decisional values items predicted participants' intention to be screened for lung cancer via LDCT in the next 6 months, we first conducted bivariate associations using *t* tests. There was a marginal association between the *pros of screening* subscale and screening intention such that the endorsement of pros was higher ($M = 22.2$, $SD = 4.3$) among those reporting being "likely" to be screened in the next 6 months versus those who reported "not likely" ($M = 20.1$, $SD = 3.8$; $t(57) = -1.7$, $p = 0.09$). The *cons of screening* were not associated with intentions to get LDCT. Adjusting for gender and recruitment source, logistic regression analyses were conducted with both subscales and the dichotomized outcome variable (unlikely/neutral vs. likely to be screened in the next 6 months), but the subscales did not significantly predict screening intentions.

Discussion

This study identified values specific to lung cancer screening that were used to develop decisional values statements that are relevant for a priority population. These statements comprised an initial tool to evaluate decisional values around lung cancer screening. The premise for the study was guided by the Ottawa Decision Support Framework that suggests that values may be specific to the decision to be made as well as the personal characteristics of those involved in making that decision [6, 16]. As a result of our discussion with key informants, statements were included in the decisional values measure that veered away from the benefits and risks of the procedure itself (e.g., How important is the idea that getting screened for lung cancer would make you feel badly about your smoking history?), and two of these items resulted in a third factor in the initial model. While the three-factor model was not retained, it is consistent with the literature that illustrates the impact of psychological variables (i.e., smoking-related stigma) on long-term smokers and their likelihood of engaging in lung cancer screening [14]. Future work in this area should include psychological-related values statements that may be important to smokers. The cross-sectional study allowed for an initial psychometric evaluation administered to a sample of low-income African American smokers, which revealed two components with very good internal consistency that explained 64% of the variance and resulted in a 12-item measure. The *pros of screening* subscale was marginally associated with screening intentions, and future interventions aimed at LDCT utilization could focus on enhancing positive beliefs rather than trying to reduce the cons of screening. Shared decision-making must cover the benefits, risks, and limitations of undergoing screening, but the framing of those messages could be manipulated (e.g., highlighting the pros of screening vs. addressing the cons of screening) to determine its impact on receptiveness by patients.

Limitations of the current study need to be considered when interpreting the results. Although the lung cancer screening-specific values statements were based on findings from key informant interviews, these discussions may not have captured all possible values related to the lung cancer screening decision. Sample limitations included lack of diversity on socioeconomic level and US geographical areas. While we did not limit the factor analysis to those eligible based upon current screening guidelines, the individuals surveyed included current and former smokers with a long-term smoking history. Given the lower quantities of cigarettes smoked by African Americans yet having a high burden of lung cancer, capturing decisional values data among individuals at varying levels of risk may have implications for

future research directions and practice [18]. This study did not capture actual screening behavior and so was not able to assess the degree to which these personal values discriminate between the behaviors, but we did evaluate associations with intention to screen. Future work should aim for a larger sample of screening eligible individuals to assess intention and actual behavior.

Utilization of existing evidence-based cancer screening tests has been lower among certain groups, including African Americans. While the reasons for lower use differ, attention must be paid to personal values that may influence lung cancer screening behavior. As healthcare institutions seek to identify patients who may benefit from lung cancer screening and engage them in the process of shared decision-making prior to LDCT, it will be important to uncover the things that are most important to diverse groups of patients. This new decisional values tool can be used to ascertain what is important to African American smokers at high risk for lung cancer and to develop new interventions that can support patients in making high-quality decisions.

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Table 1

Categories generated from key informant interviews (*n* = 9)

| Positive factors | Category | Example | Decisional values item |
|---|----------------------------------|---|--|
| Early detection Being able to treat it Extend life Better survivorship | Mortality Benefit | "Obviously that it's a screening test in kind of the whole early detection leads to earlier diagnosis and treatment and better survivorship, and all of those things are important" [Provider] | ...lowering your risk of dying from lung cancer? <i>Or</i> ...getting a lung cancer screening test that may help you live longer? |
| Being proactive Wanting to know Concern for cancer | Psychological effects (Positive) | "I'd want access to it and to be able to be in a proactive stance" [Individual] | ...getting peace of mind to find out you do not have lung cancer? ...making you feel like you are doing everything you can for your health? |
| Doctor recommendation Trust in doctor | Interpersonal relationships | "I think African Americans in particular, if they trust somebody, and if that somebody says they have lung cancer screening, you are more likely to do it than if somebody random does" [Provider] | ...following your doctor's opinion about lung cancer screening? ...thinking about family or friends who have dealt with lung cancer? |
| Family history/personal experience with cancer | | ...So I think if I knew if you get early, and I think I do know that just by reading and different people in my life that I've known, you can be cured... especially if I had a history of lung cancer in my family" [Individual] | |
| Non-invasiveness of test | Test itself | "I think positive things are knowing that it's a noninvasive test, is really important" [Provider] | ...knowing the test has little risk? |
| Negative factors | Category | Example | Decisional Values Item |
| Covered by insurance Cost Access Additional follow-up tests Overwhelmed by tests | Burden of test itself | "Well number one, I'm not sure if this test is covered by my insurance, health insurance." [Individual] | ...the out of pocket cost of the screening? ...where you have to go (testing location) to get lung cancer screening? ...the idea that lung cancer screening may lead to more testing if there is an abnormal result? |
| Age/life expectancy Other medical issues that need to be addressed | Hierarchy of life priorities | "Unfortunately once you reach a certain age, okay, you start thinking about life. And I say life instead of death." [Individual] "...do not know that screening becomes the number one priority when someone else has other medical issues to address." [Provider] | ...the idea that you would prefer to focus on other things in your life than thinking about screening for lung cancer? |
| Do not want to know results Cannot change it Fear of death due to cancer Fear of finding something Fear cancer will spread Fear of undergoing procedures Scared of results Concerns about findings Finding some other major medical problem Not picking something up that may be there | Fear/fatalism | "They do not really want to know" [Provider] "The negative things, I do not want to know, and then I think I'm at this stage, losing my mother and everything, I do not think I could handle one more thing." [Individual] | ...the idea that lung cancer screening will make you worry about lung cancer? |
| Limitations of screening | Limitations screening | <i>Note:</i> This was based upon the limitations of the test | ...the idea that lung cancer screening will not find all lung cancers or all lung cancers early? |

| Positive factors | Category | Example | Decisional values item |
|---|-------------|---|---|
| Stigma of lung cancer Guilt of smoking | Stigma | “There is a lot of baggage that comes with lung cancer screening. For smokers, that is the guilt and the shame and the nihilism on their part and on the healthcare system’s part.” [Provider] | <ul style="list-style-type: none"> ...the idea that not all patients who have lung cancer diagnosed by screening will avoid death from lung cancer? ...the idea that the lung cancer screening test might show something wrong that turns out not to be cancer? ...the idea that getting screened for lung cancer would make you feel badly about your smoking history? ...the feeling that if you had lung cancer you would feel like it was your fault? |
| Invasiveness | Test itself | “It’s still very difficult to convince people that the benefit is worth it relative to the other cancers because I think also the invasiveness of proving it is more risky than say, mammograms and finding something abnormal on a mammogram” [Provider] | <ul style="list-style-type: none"> ...knowing the test has little risk? |

Table 2Characteristics of cross-sectional study participants (*n*=119)

| Characteristic | |
|--|-----------------|
| Age (mean, sd) | 62.7 (6.3) |
| Gender, N (%) | |
| Male | 54 (46.2%) |
| Female | 63 (53.8%) |
| Education, N (%) | |
| Grade 8 or less | 6 (5.2%) |
| Grades 9 through 11 | 23 (19.8%) |
| Grade 12 or GED | 44 (37.9%) |
| College 1 year to 3 years | 34 (29.3%) |
| College 4 years or more | 9 (7.8%) |
| Marital status, N (%) | |
| Never been married | 42 (38.5%) |
| Currently married | 15 (13.8%) |
| Living with partner | 13 (11.9%) |
| Separated or divorced | 23 (21.1%) |
| Widowed | 16 (14.7%) |
| Employment, N (%) | |
| Full-time employed | 11 (9.5%) |
| Part-time employed | 12 (10.3%) |
| Not currently employed | 20 (17.2%) |
| Retired | 31 (26.7%) |
| Receiving disability | 42 (36.2%) |
| Income, N (%) | |
| < \$5,000 | 25 (23.4%) |
| \$5001–\$10,000 | 32 (29.9%) |
| \$10,001–\$20,000 | 23 (21.5%) |
| \$20,001–\$30,000 | 8 (7.5%) |
| \$30,001–\$40,000 | 5 (4.7%) |
| \$40,001–\$50,000 | 4 (3.7%) |
| >\$50,000 | 10 (9.3%) |
| Typically go to receive medical care, N (%) | |
| Primary care physician's office | 91 (85.0%) |
| Urgent care | 2 (1.9%) |
| Emergency room at the hospital | 8 (7.5%) |
| Other | 6 (5.6%) |
| Current smoker (% yes) | 94 (79.0%) |
| 20 + pack-year (% yes) | 64 (53.8%) |
| Years smoked (mean, sd, median) | 33.7 (15.4), 35 |
| Cigarettes smoked per day (mean, sd, median) | 13.4 (8.4), 10 |

| Characteristic | |
|-----------------------------------|-----------------|
| Pack-years (mean, sd, median) | 23.7 (19.9), 20 |
| Recruitment source, N (%) | |
| Public housing | 78 (65%) |
| Newspaper ad | 21 (18%) |
| Community setting (i.e., library) | 10 (8%) |
| Past study participant | 7 (6%) |
| Smoking cessation clinic | 3 (3%) |
| Decisional values, (mean, sd) | |
| Pros of screening, out of 25 | 22.1 (3.8) |
| Cons of screening, out of 35 | 28.4 (6.1) |

Note. All variables are missing less than 10% of data

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Table 3

Pattern coefficients for the retained factors for the decisional values measure

| <i>Item</i> | <i>M(SD)</i> | <i>Cons of screening factor loading</i> | <i>Pros of screening factor loading</i> |
|--|--------------|---|---|
| <i>Below are listed some things that people consider when making a decision about lung cancer screening using low-dose computed tomography. Please indicate how important these are to you by selecting "extremely important to me" to "not at all important to me." How important is...</i> | | | |
| ...lung cancer screening may lead to more testing if there is an abnormal result? | 4.2 (1.2) | 0.923 | |
| ...not all patients who have lung cancer diagnosed by screening will avoid death from lung cancer? | 4.1 (1.1) | 0.810 | |
| ...lung cancer screening will not find all lung cancers or all lung cancers early? | 4.1 (1.2) | 0.786 | |
| ...the lung cancer screening test might show something wrong that turns out not to be cancer? | 4.1 (1.1) | 0.753 | |
| ...the out of pocket cost of the screening? | 4.0 (1.3) | 0.652 | |
| ...getting screened for lung cancer would make you feel badly about your smoking history? | 4.0 (1.1) | 0.621 | |
| ...if you had lung cancer you would feel like it was your fault? | 3.9 (1.2) | 0.496 | |
| ...making you feel like you are doing everything you can for your health? | 4.5 (0.82) | | -0.918 |
| ...following your doctor's opinion about lung cancer screening? | 4.4 (0.90) | | -0.911 |
| ...knowing the test has little risk? | 4.4 (1.0) | | -0.829 |
| ...lowering your risk of dying from cancer? | 4.5 (0.84) | | -0.719 |
| ...thinking about family or friends who have dealt with lung cancer? | 4.3 (1.0) | | -0.676 |

Note: Empty cells indicate negligible loading between the corresponding item and component (< 0.400). The following five items were not retained: (1) ...getting a lung cancer screening test that may help you live longer?, (2) ...getting peace of mind to find out you do not have lung cancer?, (3) ...where you have to go (testing location) to get lung cancer screening?, (4) ...the idea that you would prefer to focus on other things in your life than thinking about screening for lung cancer?, and (5) ...the idea that lung cancer screening will make you worry about lung cancer?