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# Perceptions of Informed Decision Making About Cancer Screening in a Diverse Primary Care Population 

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#### Abstract

Objective-Our objective was to describe primary care patients' perceptions of informed and shared decision making about cancer screening tests in a diverse sample. Methods-We administered a 33 -item survey to 467 women and 257 men aged 50 years and older from seven practices in a family medicine practice-based research network. We used ordered logistic regression to assess the relationship between gender, race, education, marital status, and self-rated health with measures of patient-centered care relating to cancer screening tests, controlling for practice site. Results-Men had greater odds than women of reporting they did not know the benefits of cancer screening ( $1.46,95 \% \mathrm{CI}=1.08,1.99$ ). Compared to white respondents, black respondents reported greater odds of not knowing the benefits ( $1.70,95 \% \mathrm{CI}=1.23,2.36$ ) and risks ( $1.38,95 \%$ $\mathrm{CI}=1.00,1.90$ ) of cancer screening, of not making informed choices ( $1.50,95 \% \mathrm{CI}=1.09,2.07$ ), and that their doctor did not give them some control over their cancer screening tests (1.57, 95\% $\mathrm{CI}=1.12,2.20$ ). Low education level was also associated with lower perceptions of informed decision making. Conclusions-Patients with male sex, non-white race, and low education level reported more uncertainty about cancer screening tests and less patient-centered care.

Promoting cancer prevention through screening tests is an important part of primary care. Interactions between patients and physicians to discuss cancer screening tests are common events in primary care settings, as evidenced by national screening rates. The National Health Interview Survey reported screening rates for the year 2005 for insured patients. The rates of screening were $85.6 \%$ for Papanicolaou smears in the past 3 years in women aged $18-64$ years, $72.6 \%$ for mammography in the past 2 years in women aged 40 to 64 , and $45.7 \%$ for ever having a colorectal scope procedure in patients aged 50 and older. ${ }^{1}$ An analysis of the National Ambulatory Medical Care Survey database for trends in prostatespecific antigen (PSA) testing in visits to primary care providers by healthy men aged 35 years or older showed that PSA testing increased from $4.7 \%$ of all visits in 1995 to $7.0 \%$ of all visits in 2004, despite lack of conclusive evidence that benefits of screening outweigh harms. ${ }^{2}$

In response to recommendations from the Institute of Medicine ${ }^{3}$ and the US Preventive Services Task Force, ${ }^{4}$ primary care practices are expected to promote informed decision making so patients are informed of the risks and benefits of screening ${ }^{5}$ and facilitate shared


[^0]decision making so patients can participate in making decisions to the extent they desire. ${ }^{4}$ The Institute of Medicine considers these practices to be part of patient-centered care, ie, providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions. ${ }^{3}$

A 2004 analysis of national survey data from Veteran's Administration Hospital patients found that two components of patient-centered care-improved communication between patients and providers and continuity of care-were associated with improved preventive care delivery. ${ }^{6}$ However, other evidence suggests these markers of quality medical care are commonly not met in some settings. ${ }^{7,8}$ The patients' sex, ${ }^{9}$ age, ${ }^{10,11}$ and race ${ }^{12}$ may influence their perceptions of informed decision making.

The goal of our study was to describe primary care patients' perceptions of informed and shared decision making around cancer screening. We conducted a survey of 725 patients aged 50 years and older in seven primary care practices participating in a statewide primary care practice-based research network in North Carolina. Because women discuss more types of cancer screening tests with their primary care physicians beginning at a younger age compared to men, we hypothesized women would report greater perceptions of informed decision making about cancer screening tests. We also explored potential differences in perceptions with regard to race because these have not been well described in primary care populations with substantial representation of non-white participants.

## Methods

## Study Subjects

During the summer of 2008, every day for 3 weeks, all patients waiting to be seen for nonacute visits in seven primary care practices in North Carolina were asked to complete a questionnaire by project data collectors. These seven family medicine practices (two community/inner-city practices, three rural, two urban) had agreed to participate in the North Carolina Family Medicine Research Network's (NC-FM-RN) 2008 North Carolina Health Project (NCHP) cohort enrollment. The NC-FM-RN is a 31-clinic, practice-based, university-sponsored network devoted to research on chronic diseases in primary care; the NCHP is a patient cohort maintained by the NC-FM-RN that has been previously demonstrated to have age and racial/ethnic characteristics that are similar to those of the state of North Carolina. Assembly of the NCHP cohort, size, and participant characteristics have been previously described. ${ }^{13}$

Our goal was to recruit between 1,500 and 2,000 new patients into our patient research cohort in 2008. With each effort, we recruit practices that include diverse patient populations to reflect the diversity within the state of North Carolina. The 2008 recruitment cohort totaled 1,754 . Patients were eligible to participate if they were aged 18 years or older, presenting for a scheduled office visit in a primary care practice, and cognitively intact so they were able to consent to participation and complete the survey with assistance if needed. We excluded patients presenting for laboratory tests only, those who were acutely ill, and those who had already been approached for the survey. Informed consent to participate in a research cohort was obtained at the time participants were recruited into the NCHP.

For the current study, we analyzed individuals aged 50 years and older because participants in this age range would be more likely to have discussed cancer screening with a physician compared to patients under age and shared 50. The research protocol was reviewed and approved by the Institutional Review Board of the University of North Carolina.

## Outcomes

The outcomes for informed decision making were Likert scale scores for four questions from the Decisional Conflict Scale (DCS), a questionnaire developed to evaluate health care consumers' uncertainty in making health-related decisions, the factors contributing to the uncertainty, and health care consumers' perceived effective decision making. ${ }^{14}$ Details regarding the conceptual framework guiding development of the DCS and use of this questionnaire are available in the public domain at
http://decisionaid.ohri.ca/eval.html\#DecisionalConflictScale. A systematic review of measures used in studies of informed decision making about cancer screening reported that the DCS had high internal consistency (0.78-0.92) and test-retest reliability ( 0.81 ) and reasonable discriminant validity. ${ }^{15}$ Responses ranging from strongly agree to strongly disagree received a score from 1 to 5 respectively, with a higher score indicating more decisional conflict for three of the four questions. The four questions were derived from the three sections of the DCS (1995 validation study): decision uncertainty, factors contributing to uncertainty, and perceived effective decision making. These questions were selected because they reflected perceptions of informed and shared decision making.

Outcomes for shared decision making were Likert-scaled scores for two questions about physician participatory decision-making style derived from a survey of a cross-sectional sample of patients participating in the Medical Outcomes Study. ${ }^{16}$ Responses ranged from definitely yes to definitely no, and very often to never, with scores ranging from 1 to 5 respectively, with a higher score indicating a lower likelihood for the physician to encourage patient participation in cancer screening decisions.

## Survey Administration and Data Management

The six questions described above were included in a 33-item survey of the 2008 NCHP cohort. The introduction to the six questions stated: "These questions are about your feelings regarding cancer screening, such as mammograms to screen for breast cancer, colonoscopy to screen for colon cancer, and PSA blood test to screen for prostate cancer. Please tells us how strongly you agree or disagree with these comments by circling the number from 1 (strongly agree) to 5 (strongly disagree) that best shows how you feel about cancer screening decisions." We also requested demographic information (age, gender, race, educational level, and marital status), information on disease history, self-rated health, physician visits, and hospitalizations in the past year. Race was self-reported; participants were asked "What is your race? (please select one or more)," with answer options American Indian/Alaska Native, Asian, Native Hawaiian/Pacific Islander, Black, white. Participants who reported only American Indian/Alaska Native, Asian, or Native Hawaiian/Pacific Islander (not black or white) as their race are described as "Nonblack/nonwhite" in the results. Body mass index (BMI) was calculated from self-reported height and weight on the questionnaire.

The survey was written in English and Spanish. In 2004, the survey was translated into Spanish by a native Spanish speaker. The questionnaire was then reviewed and reverse translated by another Spanish speaker. Discrepancies in the translation were resolved and reviewed by two other staff members who were fluent in Spanish. Since then, question additions have been translated by a native Spanish speaker and then reviewed in a similar fashion. Of the 1,754 surveys for the current study, two were completed at home and mailed back to the project office. Most surveys were self-report, but 240 were administered as a whole or in part as an interview by a data collector. Copies of the survey are available upon request.

Data collectors completed a week-long training course including didactics on the medical content of the survey, role playing of patient interviews, and site visits to the practices
participating in the study. Investigators contributing questions to the survey also wrote scripts to address potential questions and ambiguous comments from participants. Survey administration was conducted during regular office hours in the waiting rooms of the practices. Patients who were unable to complete the survey at the practice were allowed to take a copy home and return the completed form by mail.

## Statistical Analysis

Data were double-entered into a Microsoft Access database (Microsoft Corp, Redmond, WA) by two different research assistants. The two data entry tables were compared for accuracy and consistency, and mismatches were corrected in the Access database. Data were recorded as missing if items were unmarked, if multiple responses were marked for a singleanswer item, or if comments were written that did not match any of the response options.

Descriptive statistics were tabulated for all of the participants. We tested for differences in survey response items by sex because cancer screening tests would differ for women (Pap smears, mammograms, colorectal cancer screening) compared to men (screening for prostate cancer and colorectal cancer).

For the ordinal response items, we calculated the $P$ value for the Mantel-Haenszel score test for trend of odds in women versus men for a one-unit increase in the survey response item rating, controlling for practice site. ${ }^{17} \mathrm{We}$ used ordered logistic regression to assess the relationship of the ordinal response variable for each survey question to the independent variables sex, race, education, marital status, and self-rated health, controlling for practice site. Specifically, using proportional odds models, ${ }^{18}$ we modeled cumulative logits corresponding to the log odds of a lower response on the Likert scale to a higher response. A complete case analysis (only cases with complete data were analyzed) was performed using the Stata SE 9.2 software. ${ }^{19}$ Using a Bonferroni multiplicity adjustment for the six outcome variables, a $P$ value less than $.05 / 6=.008$ was considered statistically significant, whereas . $05>P>.008$ was considered nearly significant.

## Results

Of 2,641 eligible patients aged 18 years and older who were approached, 1,754 completed surveys, for a $66.4 \%$ response rate. A total of 240 Spanish language questionnaires were completed, and 60 were completed as a whole or in part as an interview. In those practices with Spanish-speaking patients, data collectors were fluent in Spanish. Of the 1,754 respondents, the 467 women and 257 men who were aged 50 years and older were analyzed. Seven primary care practices were represented in this sample, with 16 to 180 participants from each practice.

The mean age of respondents was 62.2 years (range 50 to 95 years), and $64.5 \%$ of the respondents were female (sex not reported by one respondent) (Table 1). Black ( $44.1 \%$ ) and white ( $45.7 \%$ ) participants were equally represented, with other races accounting for $10.2 \%$ of the total. Although participants were asked to select one or more racial group from a list, every participant marked only one race.

## Distribution of Survey Responses

Almost $40 \%$ of the participants reported feeling unsure about what to do about cancer screening tests ( $16.1 \%$ strongly agree, $22.6 \%$ agree); a similar number disagreed with this statement, and $16.3 \%$ neither agreed nor disagreed (Table 2). Most participants reported they knew the benefits of cancer screening ( $43.2 \%$ strongly agree, $33.2 \%$ agree), and more than half stated they knew the risks ( $27.3 \%$ strongly agree, $29.8 \%$ agree). Nearly $70 \%$ of the participants reported they had made informed choices about cancer screening. Most said
their regular doctor asks for patient input regarding cancer screening tests ( $39.9 \%$ definitely yes, $40.7 \%$ yes). However, fewer patients reported that their doctor gives them some control over these tests ( $22.0 \%$ definitely yes, $28.7 \%$ yes, $19.4 \%$ definitely no). After adjusting for practice site, no statistically significant differences were seen in the trend of odds for responses from women compared to men.

## Differences by Sex and Race

In the multivariable analysis of survey responses (Tables 3 A and 3 B ), men had greater adjusted odds than women of reporting they did not know the benefits of cancer screening (1.46, $95 \% \mathrm{CI}=1.08,1.99$ ). Sex was not significantly associated with a difference in any other response item.

Black respondents had greater adjusted odds than white respondents of reporting they did not know the benefits $(1.70,95 \% \mathrm{CI}=1.23,2.36)$ or risks $(1.38,95 \% \mathrm{CI}=1.00,1.90)$ of cancer screening tests, had not made informed choices about these tests ( $1.50,95 \% \mathrm{CI}=1.09$, 2.07), and that their doctor did not give them some control over their cancer screening tests ( $1.57,95 \% \mathrm{CI}=1.12,2.20$ ). Non-black/non-white women reported responses similar to black women regarding the risks of, and whether their doctor would give them some control over, cancer screening tests.

## Differences by Education and Self-rated Health

Respondents with more education (associate degree and above versus less than high school education) reported greater adjusted odds of not feeling unsure about their decisions about cancer screening tests $(2.05,95 \% \mathrm{CI}=1.32,3.17)$ and lower adjusted odds of feeling they did not know the benefits of cancer screening ( $0.41,95 \% \mathrm{CI}=0.26,0.64$ ) (Table 3 B ). No statistically significant associations were found between self-rated health and the outcomes in the adjusted analysis.

## Discussion

Our survey of 725 patients aged 50 years and older from seven family medicine practices participating in a statewide practice-based research network showed a wide distribution of perceived certainty and physician support in decision making for cancer screening tests. In the adjusted analysis, men had greater odds of reporting they did not know the benefits of cancer screening; there was no difference in responses between women and men for the other response items. Black respondents reported less favorable measures of informed and shared decision making compared to white respondents on four of six response items. Non-black/non-white race and education level were significant in fewer response items.

Few direct comparisons of sex-related differences in elements of informed decision making have been conducted. In a qualitative study comparing beliefs about informed or shared decision making about prostate cancer screening in 90 African American, Hispanic, and non-Hispanic white men and women (overall sample $53 \%$ male), women expressed a strong preference for their husbands and male relatives to obtain prostate cancer screening, ${ }^{20}$ and some women expressed concern that a discussion of the harms of prostate cancer screening might dissuade men from seeking screening. ${ }^{21}$ Our study showed that women perceived a comparable degree of certainty about the benefits and risks of cancer screening tests compared to men when asked about cancer screening in general. The greatest sex-related difference in our results was that, compared to women, men reported they were less likely to report certainty about the benefits of cancer screening. The results might reflect the longer and more frequent exposure to cancer screening for women (because of Pap smears) compared to men. However, the more complicated discussion of the benefits and risks of
prostate cancer screening could contribute to the men's greater uncertainty. More extensive, disease-specific survey questions would be needed to determine whether certain cancer tests are associated with lower perceptions of patient-centered care.

Our study included greater proportions of minority respondents ( $44 \%$ black, $10.2 \%$ non-black/non-white) than prior research on this topic. The racial distribution was significantly different from that in the 2008 Behavioral Risk Factor Surveillance System data, which had a distribution of $17.5 \%$ black, $69.3 \%$ white, and $13.2 \%$ other/multiracial status reported by residents of the state of North Carolina. ${ }^{22}$ Considering the substantial non-white representation from multiple practice sites in our study, our findings of racial disparities in perceived informed decision making likely represent a real phenomenon that merits attention. Black patients' preferences regarding informed decision making may differ from a traditional model by placing more emphasis on the importance of information sharing rather than decision-making sharing. ${ }^{23}$ Also, a cohort study of 142 African-American patients and 110 white patients receiving care from 31 physicians ( 18 African-American, 13 white) found an association between race concordance of patient-physician and higher patient ratings of care, independent of patient-centered communication. ${ }^{24}$ Physicians must consider racial differences to adequately tailor preventive care to patient preferences.

## Study Limitations

Several limitations affect the interpretation of our results. We used published questions on decisional conflict, adapted for the cancer screening topic. Due to space restrictions in the full survey (which covered several health care topics), we could only include one or two questions from each category of O'Connor's 1995 Decisional Conflict Scale. We could not calculate subscore totals since only a portion of the questions for each category of the original scale was represented; the reduced set of questions we selected has not been validated independently.

We only measured patients' self-reported certainty about cancer screening and of their doctors' actions in screening decisions. We do not have documentation of whether informed decision making actually did or did not take place. A 2009 survey study by Gigerenzer et al found that the great majority of respondents systematically overestimated the benefits of mammography and PSA screening and that frequent consultation of sources of medical information (including physicians) was not associated with more realistic knowledge of the benefits of screening. ${ }^{25}$ In light of these results, we estimate that our participants' actual knowledge of the benefits and risks of cancer screening would be lower than their perceived certainty reported in our survey. Data on screening tests received by our survey respondents were not available, so we could not compare differences between screened and unscreened patients. In the lead-in for the screening questions, women were asked to consider breast and colon cancer screening, but men were asked to consider colon cancer screening and PSA testing. Differences in attitudes toward different screening tests could explain some of the sex differences observed. Variation in patients' understanding of the meaning of "screening" could also have influenced their reporting. Black and white patients were well represented in the sample; however, results from the 70 non-black/non-white patients may not be generalizable due to the small number.

## Conclusions

Increased physician effort to involve men, non-white patients, and patients with lower educational level in discussions about cancer screening could improve patients' perceptions of informed decision making in primary care practices. A conscientious, individualized approach toward the patient is a necessary first step toward improving informed cancer screening decisions in these groups.

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Table 1
Characteristics of the Participants $(n=725)$

| Characteristic | Value, n (SD or \%) |
| :---: | :---: |
| Mean age, years (SD) | 62.2 (9.5) |
|  | range 50-95 |
| Mean body mass index (SD) | 30.4 (7.3) |
| Female, n (\%) | 467 (64.5) |
| Race, n (\%) |  |
| Black | 302 (44.1) |
| White | 313 (45.7) |
| American Indian or Alaska native | 13 (1.90) |
| Asian or Hawaiian/Pacific Islander | 10 (1.46) |
| Other | 47 (6.86) |
| Education, n (\%) |  |
| 8th grade or less | 82 (11.7) |
| Some high school | 115 (16.5) |
| High school grad | 190 (27.2) |
| Some college | 145 (20.7) |
| Associate or Bachelor's degree or postgraduate education | 167 (23.9) |
| Marital status, n (\%) |  |
| Married | 342 (48.9) |
| Widowed, separated, divorced or lives with partner | 307 (43.9) |
| Never married | 51 (7.3) |
| Self-rated health, n (\%) |  |
| Excellent | 24 (3.3) |
| Very good | 132 (18.3) |
| Good | 244 (33.8) |
| Fair | 239 (33.1) |
| Poor | 84 (11.6) |

Note: $\mathrm{n}=685$ for age, 679 for body mass index, 724 for sex, 685 for race, 699 for education, 700 for marital status, 723 for self-rated health.

Table 2
Survey Responses in Women ( $n=467$ total) and Men ( $n=257$ total) Aged 50 and Older
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| Survey Question | Sex |  |  | Response (\%) |  |  | P Value* |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  | Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |  |
| I'm unsure about what to do when asked to make decisions about cancer screening tests. | $\mathrm{F}(\mathrm{n}=407)$ | 17.9 | 22.6 | 16.0 | 19.7 | 23.8 | . 42 |
|  | M ( $\mathrm{n}=226$ ) | 12.8 | 22.6 | 16.8 | 25.7 | 22.1 |  |
| I feel I know the benefits of cancer screening. | F ( $\mathrm{n}=416$ ) | 45.4 | 32.7 | 9.4 | 7.2 | 5.3 | . 09 |
|  | M ( $\mathrm{n}=228$ ) | 39.0 | 34.2 | 9.7 | 11.8 | 5.3 |  |
| I feel I know the risks of cancer screening. | F (n=404) | 29.5 | 29.5 | 17.6 | 16.1 | 7.4 | . 22 |
|  | M ( $\mathrm{n}=226$ ) | 23.5 | 30.5 | 19.5 | 20.8 | 5.8 |  |
| I feel I have made informed choices about cancer screening. | F (n=411) | 34.3 | 33.8 | 17.3 | 9.5 | 5.1 | . 76 |
|  | M ( $\mathrm{n}=227$ ) | 33.9 | 34.4 | 14.5 | 13.2 | 4.0 |  |
|  |  | Definitely Yes | Yes | Maybe | No | Definitely No |  |
| If there were a choice between cancer screening tests, would your regular doctor ask you to help make the decision? | F (n=430) | 40.5 | 39.1 | 14.9 | 4.4 | 1.2 | . 75 |
|  | M N=226) | 38.9 | 43.8 | 13.3 | 2.2 | 1.8 |  |
|  |  | Very Often | Often | Sometimes | Rarely | Never |  |
| How often does your regular doctor make an effort to give you some control over your cancer screening tests? | F (n=397) | 24.9 | 26.7 | 18.1 | 10.6 | 19.7 | . 38 |
|  | M ( $\mathrm{n}=195$ ) | 15.9 | 32.8 | 25.1 | 7.2 | 19.0 |  |

$P$ value for Mantel-Haenszel score test for trend of odds in women versus men, controlling for practice site. F=female, M=male
Patient Characteristics Associated With Survey Responses in Multivariable Analyses, Adjusted Odds Ratios (n=592 to 656)

| Survey response | Adjusted OR (95\% CI) ${ }^{\boldsymbol{a}}$ |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | Male ${ }^{\text {b }}$ | Black ${ }^{\boldsymbol{c}}$ | Non-black, Non-white ${ }^{\text {c }}$ | High Level of Education ${ }^{d}$ | Married ${ }^{\text {e }}$ | Poor Self-rated Health $f$ |
| Does not feel unsure about decision | 1.07 (0.80, 1.44) | 0.82 (0.60, 1.13) | 0.60 (0.35, 1.03) | 2.05 (1.32, 3.17) | 1.25 (0.77, 2.02) | 0.85 (0.57, 1.27) |
| Does not know the benefits of cancer screening | 1.46 (1.08, 1.99) | 1.70 (1.23, 2.36) | 1.45 (083, 2.52) | 0.41 (0.26, 0.64) | 0.81 (0.49, 1.14) | 1.15 (0.77, 1.74) |
| Does not know the risks of cancer screening | 1.31 (0.97, 1.77) | 1.38 (1.00, 1.90) | 1.92 (1.11, 3.33) | 0.75 (0.49, 1.16) | 0.99 (0.61, 1.62) | 1.14 (0.76, 1.71) |
| Did not make informed choices about cancer screening | 1.13 (0.83, 1.53) | 1.50(1.09, 2.07) | 1.14 (0.67, 1.94) | 0.70 (0.45, 1.09) | 0.77 (0.47, 1.27) | 1.48 (0.99, 2.22) |
| Doctor did not ask you to help make decision | 0.95 (0.70, 1.30) | 1.02 (0.73, 1.41) | 1.55 (0.90, 2.67) | 0.99 (0.64, 1.55) | 1.00 (0.59, 1.70) | 0.95 (0.63, 1.43) |
| Doctor did not give you some control over your cancer screening tests | 1.34 (0.98, 1.84) | 1.57(1.12, 2.20) | 1.88 (1.09, 3.25) | 0.72 (0.46, 1.13) | 0.77 0.45, 1.33) | 0.85 (0.56, 1.27) |

CI -confidence interval, OR —odds ratio.
Statistically significant associations using Bonferroni adjustment ( $P<.008$ ) are in bold type. Nearly significant results $(.0>P>.008)$ are in italics.
${ }^{a}$ Odds ratios for higher versus lower response of Likert scale of the response from proportional odds models, adjusted for sex, race, education, marital status, self-rated health, practice site
$b_{\text {Male versus female (female is reference category) }}$
${ }^{c}$ Black versus white; non-black, nonwhite versus white (white is reference category)
 significant)
$f_{\text {Poor/fair self-rated health versus excellent/very good (comparison of "good" versus "fair/poor" self-rated health was not statistically }}$


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