

Lack of Shared Decision Making in Cancer Screening Discussions

Results from a National Survey

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Background: Clinicians are encouraged to support patients in achieving shared decision making (SDM) for cancer screening.

Purpose: To describe decision making processes and outcomes for cancer screening discussions.

Methods: A 2011 national Internet survey of adults aged ≥ 50 years who made cancer screening decisions (breast, BrCa; colorectal, CRC; prostate, PCa) within the previous 2 years was conducted. Participants were asked about their perceived cancer risk; how informed they felt about cancer tests; whether their healthcare provider addressed pros/cons of testing, presented the option of no testing, and elicited their input; whether they were tested; and their confidence in the screening decision. Data were analyzed in 2013–2014 with descriptive statistics and logistic regression.

Results: Overall, 1,134 participants (477 men, 657 women) aged ≥ 50 years made cancer screening decisions, and 1,098 (354, BrCa; 598, CRC; 146, PCa) decisions were discussed with a healthcare provider. Most discussions (51%–67%) addressed pros of screening some or a lot, but few (7%–14%) similarly addressed cons. For all cancer screening decisions, providers usually (63%–71%) explained that testing was optional, but less often asked women (43%–57%) than men (70%–71%) whether they wanted testing. Only 27%–38% of participants reported SDM, 69%–93% underwent screening, and 55%–76% would definitely make the same decision again. Perceived high/average cancer risk and feeling highly informed were associated with confidence in the screening decision.

Conclusions: Discussions often failed to provide balanced information and meet SDM criteria. Supporting SDM could potentially improve the quality of cancer screening decisions. (Am J Prev Med 2014;47(3):251–259) Published by Elsevier Inc. on behalf of American Journal of Preventive Medicine

Introduction

Cancer screening decisions are complex because they have uncertain and multiple outcomes, can extensively affect patients, and are controversial.¹

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Clinicians are encouraged to support patients in achieving shared decision making (SDM) by informing them that there is a decision to be made, inviting them to participate in the decision, presenting them with information about the benefits and harms of alternative options, and helping them to make decisions concordant with their personal values.² However, a previous publication found that cancer screening decisions often fell short of this ideal.³ The National Survey of Medical Decisions (DECISIONS) study was a nationally representative telephone survey conducted in 2006–2007 of adults facing common medical decisions, including screening for breast cancer (BrCa); colorectal cancer (CRC); or prostate cancer (PCa).⁴ Approximately 20% of the time, DECISIONS participants reported being screened without any discussion. According to participants, when healthcare providers discussed screening,

they did not routinely present balanced information about the benefits and harms of screening or ask participants' preferences. Additionally, participants often overestimated how informed they were about the cancer tests, as evidenced by poor performance on knowledge questions.

Since the last survey, patient advocacy groups,⁵ professional associations,⁶ the Patient Protection and Affordable Care Act,⁷ and influential guidelines^{8,9} now emphasize the importance of supporting SDM, including for PCa screening decisions by men of any age and BrCa screening decisions by women in their forties. The U.S. Preventive Services Task Force (USPSTF) had previously supported SDM for CRC screening in those aged >75 years.¹⁰ To determine whether such recommendations have improved the quality of decisions, a national Internet survey was conducted to characterize the current content, processes, and outcomes of discussions for preference-sensitive decisions, including cancer screening.¹¹

Methods

Subjects

The survey methodology has been previously described.¹¹ Briefly, Knowledge Networks (knowledgenetworks.com) surveyed adults aged ≥ 40 years between November 2 and December 13, 2011. Knowledge Networks sampled households from its Knowledge-Panel, a probability-based web panel designed to be representative of adults living in U.S. households. The New England IRB exempted this study from review.

Screener questions identified respondents who had experienced or discussed with a healthcare provider one of ten medical decisions (screening for CRC, BrCa, or PCa; medication for hypertension, hypercholesterolemia, depression; or surgery for arthritis of the knee or hip, cataracts, or low back pain) within the past 2 years. These eligible respondents were then asked about their interactions with healthcare providers. Respondents who reported engaging in more than two decisions were assigned to complete just two survey modules using a probability selection that gave less common decisions a higher probability of selection.

The present analyses focus primarily on the subset of participants aged ≥ 50 years who completed cancer screening survey modules. The age group was restricted because, when the survey was conducted, there were no recommendations to routinely screen younger, average-risk individuals for CRC¹² and recommendations for BrCa and PCa screening were inconsistent.^{8,9,13,14} However, data on mammography decisions among women in their forties were also analyzed because the USPSTF has recommended that these women make informed decisions.⁹

Baseline Characteristics

Sociodemographic characteristics, including age, gender, race/ethnicity, marital and work status, income, education, and health insurance coverage were assessed. Participants rated their health status and whether they considered themselves to be at low, average, or high risk for the cancer in question. Participants were

asked to rate how well informed they felt about the cancer screening tests using a 0–10 scale, with 0 being *not informed at all*, and 10 being *extremely well informed*.

Patient–Provider Communications and Decision Processes

Survey items, based on the DECISIONS study,⁴ were used to characterize the interactions between participants and providers when discussing cancer screening. A decision process score was created for each decision group that ranged from 0 to 4 by assigning one point each if the provider discussed (1) pros or (2) cons of testing some or a lot (compared to none or a little); (3) explained the option of no testing; and (4) asked whether the participant wanted to be tested. Based on a theoretical model,^{2,15} higher scores were interpreted as being more consistent with SDM. Participants were asked whether providers offered opinions regarding screening and made explicit screening recommendations, and who was mainly responsible for making the decision (participant, provider, or shared). Participants were also asked whether they underwent testing and *If you knew then what you know now, do you think you would make the same decision about cancer screening (definitely yes, probably yes, probably no, definitely no)?* Discussions were characterized as either being first-time or repeat (previously discussed).

Statistical Analyses

Analyses were performed in 2013–2014 using IBM SPSS, V21.0 (Endicott NY), with the IBM SPSS Complex Samples 20 module applied to account for the complex design. Data were weighted to adjust for nonresponse so that responders to the initial screener questions matched the age, race, gender, and geographic characteristics of the U.S. population aged ≥ 40 years, based on Census Bureau data.¹⁶ Responses were also weighted to adjust for the different probabilities of being selected for the various survey modules. Adjusted ANOVA and chi-square analyses, respectively, were used to compare means of continuous variables and categorical discussion characteristics across the four decision groups (CRC screening results were reported separately for each gender). Global *p*-values were reported for these four-group comparisons; when the *p*-value was significant (< 0.05), selected pairwise post hoc comparisons were performed. Discussion characteristics and outcomes were also compared for participants reporting first-time versus repeat discussions for all decision groups and for women in their forties versus women aged ≥ 50 years who faced BrCa screening decisions. Finally, logistic regression analyses were used to model factors associated with decision confidence (dichotomizing as *would definitely make the same decision again* versus all other responses), including sociodemographic factors, self-reported health status, cancer risk belief, feeling informed about cancer screening tests, decision quality and process measures, cancer screening decision group, and discussion status (first versus repeat). Results were stratified by whether the participant underwent testing; *p*-values < 0.05 were considered significant.

Results

Among the 5,682 surveyed participants, 3,396 answered baseline survey questions and 2,788 reported making one

Table 1. Participant characteristics by cancer screening decision, weighted percentages^a

Variable	Breast cancer (n=354)	Colorectal cancer (women; n=323)	Colorectal cancer (men; n=275)	Prostate cancer (n=146)	p-value
Age (years)					0.57
50–59	46	42	37	33	
60–69	30	33	33	33	
≥ 70	25	25	30	34	
Race/ethnicity					0.14
White	74	78	71	78	
African American	10	12	12	2	
Hispanic	10	4	10	15	
Other	6	7	7	5	
Marital status					<0.001
Married or living with partner	59	55	78	76	
Education					0.05
≤ High school	48	40	39	32	
Some or 2-year college	30	31	24	30	
≥ 4-year college	23	30	37	38	
Work status					0.49
Working	43	47	41	36	
Not working (not retired)	16	16	16	13	
Retired	41	36	43	51	
Household income (\$)					0.15
< 50,000	50	47	35	39	
50,000–99,999	31	30	37	35	
≥ 100,000	19	23	28	26	
Health insurance coverage	96	93	96	95	0.45
Self-reported health status					0.97
Excellent/very good	48	46	49	52	
Good	40	43	39	35	
Fair/poor	12	11	13	12	
Cancer risk belief					0.003
High risk	12	13	8	6	
Average risk	41	40	55	64	
Low risk	47	47	37	30	

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or more of the ten target decisions (Figure 1). Overall, 2,718 (97%) of the eligible participants completed the survey, for a response rate of 58%. The 2,333 subjects who made cancer-screening decisions were identified and 1,452 were randomly selected to complete cancer screening surveys. Among this group, 1,134 (477 men, 657 women) were aged ≥ 50 years. These subjects completed 1,414 cancer screening surveys modules (179 women completed BrCa and CRC modules, 101 men completed CRC and PCa modules). The 1,098 cancer screening decisions discussed with healthcare providers were evaluated.

Characteristics of the study participants are shown in Table 1. Overall, the mean age was 63.2 years; most participants were white, married or living with a partner, and educated beyond high school. Nearly all were insured, and about half reported being in excellent/very good health. Few considered themselves at high risk for developing cancer and most considered themselves well informed about cancer screening tests. However, women were more likely than men to consider themselves at high risk for cancer and highly informed about cancer screening tests.

Table 2 characterizes the content of screening discussions. Most discussions routinely addressed the pros of testing some or a lot (51%–67%); however, few addressed the cons of testing (7%–14%). Participants reported that

Table 1. Participant characteristics by cancer screening decision, weighted percentages^a (continued)

Variable	Breast cancer (n=354)	Colorectal cancer (women; n=323)	Colorectal cancer (men; n=275)	Prostate cancer (n=146)	p-value
Feeling informed					< 0.01
0–7	38	37	45	55	
8–9	31	39	41	28	
10 (highest)	31	25	14	17	

Note: Boldface indicates statistical significance ($p < 0.05$).

^aWeighted for age, race, gender, and geographic region.

healthcare providers usually explained that the participant could choose whether to have a test, though more often to men than women. Participants usually reported being asked whether they wanted to be tested (43%–71%), although less often for BrCa screening (43%). The mean decision process scores were low, ranging from 1.7 reported by women discussing BrCa screening to 2.3 reported by men discussing CRC screening.

Participants also reported that most healthcare providers expressed opinions about the cancer screening testing, which primarily favored screening. Most participants reported being mainly responsible for making the final decision (45%–69%) or that they made the decision with the provider (27%–38%). However, participants completing the PCa module were significantly more likely than those completing any other module to indicate that the healthcare provider was primarily responsible for making the decision ($p < 0.02$). Among participants discussing CRC screening, men had slightly higher decision process scores than women (2.3 vs 2.0, $p = 0.03$) and were more likely to report being asked by the healthcare provider whether they wanted testing (71% vs 57%, $p = 0.02$).

Overall, 77% of participants underwent screening, ranging from 69% of women discussing CRC to 93% of men discussing PCa screening (global $p = 0.03$). The majority reported that they definitely would make the same decision again about whether to undergo screening, ranging from 55% for PCa screening to 76% for BrCa screening. However, men who underwent screening for PCa were significantly less confident with their decision than women screened for BrCa (55% vs 76%, $p = 0.02$). Men and women were equally likely to undergo CRC screening and indicate that they would definitely make the same decision again.

Screening discussions and outcomes were also evaluated according to whether this was a first-time or repeat discussion. Overall, only 21% of the discussions were first-time. There were no significant differences for decision process scores, provider recommendations, or participant

involvement according to whether this was a first-time discussion. Participants were consistently less likely to undergo screening after a first-time discussion than a repeat discussion, with significant differences for women discussing CRC or BrCa and for men discussing PCa.

BrCa screening discussions and outcomes between women in their forties and those aged ≥ 50 years were

also compared. Younger women had higher SES than older women, were less likely to consider themselves at low risk for BrCa risk (38% vs 47%, $p < 0.01$), and equally likely to feel extremely well informed about screening tests. The decision process elements, provider recommendations, and screening decisions were similar for both age groups. The only difference emerged for decision confidence; younger women were more likely to respond that they would probably or definitely not make the same decision again (8% vs 2%, $p = 0.03$). Screening discussions and outcomes between participants stratified at age 75 years were compared for each cancer module. There were no significant differences in the decision processes or outcomes, but statistical power was limited because only 7.6% of the participants were aged > 75 years.

Table 3 shows that belief of being at average/high risk for cancer and feeling highly informed about the cancer screening test were significantly associated with participants reporting that they would definitely decide again to be screened. Men who underwent screening for PCa reported significantly less confidence in their decision than women screened for BrCa ($p < 0.001$).

Among participants who did not undergo screening (data not shown), feeling highly informed about the cancer screening test was significantly associated with decision confidence (OR=5.0, 95% CI=1.7, 10.0). Those reporting that the healthcare provider was mainly responsible for the screening decision were significantly less confident (OR=0.1, 95% CI=0.0, 0.6) than those making a shared decision.

Discussion

Achieving SDM for cancer screening is challenging. The nationally representative sample of adults who had recently faced screening decisions reported that healthcare providers often failed to provide balanced information, particularly about the cons of screening. Healthcare providers did not

Table 2. Cancer screening discussions and outcomes by cancer type, weighted percentages^a

Variable	Breast cancer (n=354)	Colorectal cancer (women; n=323)	Colorectal cancer (men; n=275)	Prostate cancer (n=146)	p-value
Discussion content					
Discussed reasons to have test (pros)					0.07
Not at all/a little	47	41	33	48	
Some/a lot	53	59	67	51	
Discussed reasons not to have test (cons)					0.21
Not at all/a little	92	87	87	93	
Some/a lot	8	13	14	7	
Healthcare provider explained that patient could choose whether to have test	63	68	76	71	0.15
Healthcare provider asked if participant wanted test	43	57	71	70	<0.001
M (SE) decision process score	1.7 (0.1)	2.0 (0.1)	2.3 (0.1)	2.0 (0.1)	<0.001
Decision process score^b					<0.01
0	19	15	8	11	
1	25	22	16	20	
2	31	23	26	37	
3 or 4	25	39	50	33	
Recommendation from provider					
Expressed opinion about test	68	77	85	76	0.02
Recommended having test	67	75	81	72	0.38
Participant involvement					
Who made final decision					<0.01
Mainly participant's decision	69	54	57	45	
Mainly healthcare provider's decision	5	8	5	21	
Made the decision together	27	38	38	34	
Discussion outcomes					
Screened decision: screened	85	69	71	93	<0.001
Would make the same decision again					0.02
Definitely yes	76	63	69	55	
Probably yes	22	28	24	38	
Probably no/definitely no	2	9	6	7	

Note: Boldface indicates statistical significance ($p < 0.05$).

^aWeighted for age, race, gender, and geographic region.

^bBased on the presence of the previous four decision factors, higher scores associated with more shared decision making.

routinely invite participants to engage in decision making or elicit preferences for testing. These decision process elements were similarly lacking for first-time and repeat discussions and for mammography discussions for women older and younger than age 50 years. Most participants underwent screening, and the majority reported that they would definitely make the same screening decision again.

The lack of SDM for cancer screening decisions is consistent with findings from the earlier DECISIONS study.³ In DECISIONS, subjects reported addressing the pros of screening in >90% of cancer screening discussions, but only 19% (BrCa) to 30% (PCa) of discussions addressed the cons of screening. Providers elicited subjects' preferences in only 31% (CRC women) to 57% (PCa) of the discussions.³ The trend is disconcerting because widely publicized BrCa and PCa screening guidelines highlighting the need for supporting informed decisions were published between the surveys.^{8,9} Although both surveys used nationally representative samples, they cannot be compared directly because DECISIONS was a telephone survey and the current survey was web-based. Nonetheless, our findings are consistent with other reports confirming persistent problems with decision making for PCa, CRC, and BrCa screening decisions.^{17–24}

Given the recent national dialogue emphasizing support for informed decision making, we expected that participants facing a first-time screening

Table 3. Factors associated with decision confidence^a of screened participants

Variable	Univariate OR (95% CI)	p-value	Multivariate OR (95% CI)	p-value
Age, 10-year intervals	1.0 (0.8, 1.3)	0.93	1.1 (0.8, 1.5)	0.68
Race/ethnicity				
Non-Hispanic whites, ref				
Other	0.8 (0.4, 1.3)	0.34	0.7 (0.4, 1.3)	0.29
Marital status				
Married/living with partner, ref				
Other	0.5 (0.3, 0.8)	<0.01	0.6 (0.4, 1.0)	0.06
Education				
≥4-year college, ref				
Other	0.7 (0.5, 1.1)	0.15	0.7 (0.5, 1.2)	0.22
Self-reported health status				
Excellent/very good, ref				
Good/fair/poor	0.6 (0.4, 0.9)	0.01	1.3 (0.8, 2.0)	0.30
Cancer risk belief				
Low, ref				
Average/high	1.6 (1.0, 2.5)	0.05	1.7 (1.0, 2.8)	0.03
Feeling informed about cancer tests				
Highly informed=10, ref				
Less informed=0–9	0.3 (0.1, 0.6)	0.001	0.2 (0.1, 0.6)	0.001
Decision process score				
High=3 or 4, ref				
Low=0–2	0.6 (0.4, 1.1)	0.08	0.8 (0.5, 1.4)	0.47
Provider recommended having test				
No recommendation/recommended against, ref				
Provider recommended test	1.7 (1.0, 2.8)	0.04	1.7 (0.9, 3.0)	0.09
Who made final decision				
Made the decision together, ref				
Mainly participant	0.9 (0.5, 1.5)	0.65	0.9 (0.5, 1.7)	0.85
Mainly healthcare provider	0.3 (0.1, 0.6)	0.001	0.5 (0.2, 1.1)	0.08
First-time discussion				
No, ref				
yes	0.6 (0.3, 1.1)	0.08	0.7 (0.4, 1.4)	0.36
Cancer screening group				
Breast cancer, ref				
Colorectal cancer women	0.5 (0.3, 0.9)	0.03	0.6 (0.3, 1.1)	0.11
Colorectal cancer men	0.8 (0.5, 1.5)	0.57	0.8 (0.4, 1.6)	0.54
Prostate cancer	0.3 (0.2, 0.6)	<0.01	0.3 (0.1, 0.5)	<0.01

Note: Boldface indicates statistical significance ($p < 0.05$).

^aWould definitely make the same decision again.

discussion would be more likely to report processes consistent with SDM than those who had previously discussed screening. However, decision quality was poor for both first-time and repeat screening discussions, although it could not be determined whether the repeat screening discussions were held with the same provider. No other studies have characterized whether decision processes and outcomes change with repeat screening discussions.

The 2009 USPSTF recommendation that women aged <50 years make informed decisions regarding mammography screening⁹ created controversy and confusion.^{25,26} The Task Force did not recommend against screening younger women, but rather encouraged providers to support younger women in making decisions consistent with their values. The expectation was that discussion quality would be higher among younger women. Instead, SDM elements were similarly lacking for both age groups, particularly discussions about reasons against undergoing mammography. Investigators previously reported in 2003 that mammography decisions among younger women were often poorly informed, leading them to be less engaged in decision making and have higher decisional conflict.¹⁸ Our findings point to an unfortunate persistence of poor decision making among younger women, possibly suggesting that healthcare providers are not being trained or encouraged to carry out SDM with their patients or that they lack the time for conducting these discussions.

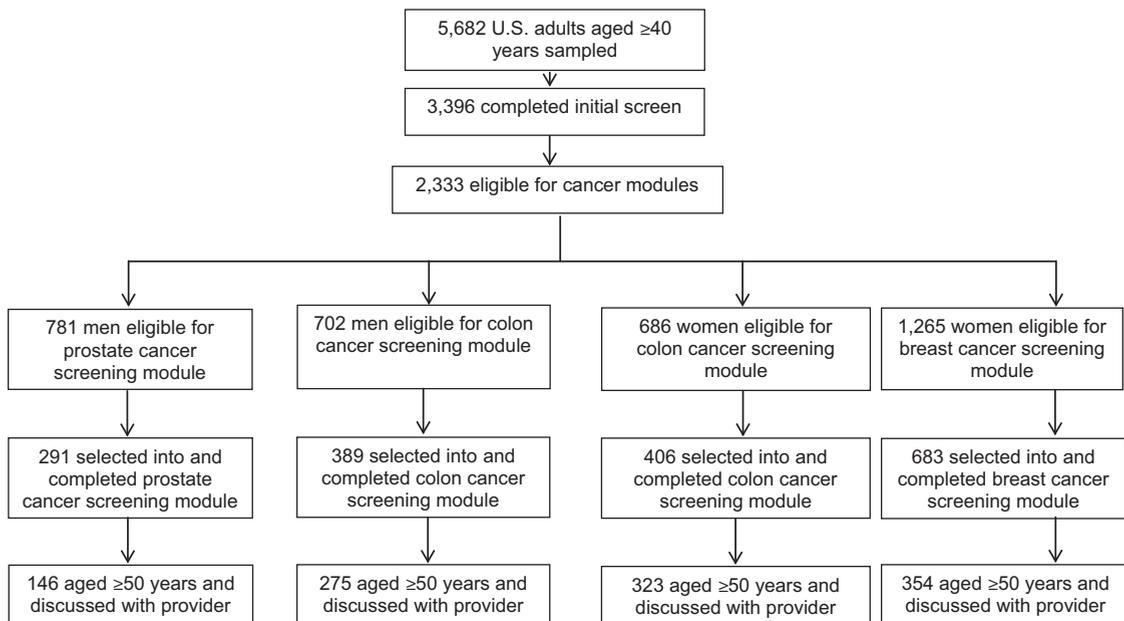


Figure 1. Cohort assembly

Although men and women were equally likely to report undergoing CRC screening, men reported higher-quality discussions. This finding might reflect a reporting bias because men have been shown to be more likely to over-report undergoing CRC screening than women,²⁷ but could also represent differences in provider behaviors that warrant further study.

There were too few older adult participants to meaningfully characterize their screening experiences. Although the USPSTF has recommended individualizing screening decisions in older adults, a recent narrative review highlighted the need to better address the issues of increased harm, quality-adjusted survival, and patients' preferences when considering screening older populations.²⁸ Other investigators have shown that decision aids improve decision making for older women considering mammography.²⁹

Most subjects underwent screening and reported that they would definitely make the same decision again. The perception of being at average/high risk for cancer and feeling highly informed about the screening tests were the factors most highly associated with decision confidence. However, it was previously shown that patients markedly overrate lifetime risks for cancer diagnosis and death and perform poorly on knowledge tests.³ Given that participants also did not recall being informed about the potential harm of screening, the high degree of confidence with screening could reflect poor-quality decisions. Patients are positively reinforced for undergoing cancer screening because they can be grateful for both the reassurance of a negative result—even when tests have substantial false-negative

rates—and for early cancer detection and treatment following a positive result—even when the value of screening and treatment is uncertain or minimal.³⁰ Alternatively, given the high general enthusiasm for screening,³¹ discussion recall might have been biased because screened participants would be less likely to retain negative information. Additionally, the self-reported accounts of screening discussions could have occurred up to 2 years before the survey.

Although a national sampling frame was used, our results might be less generalizable to minority and lower-SES populations with less access to health care. However, other studies have shown that affluent and educated patients find it challenging to engage physicians in SDM,³² making it unlikely that patients with lower health literacy and SES would have higher decision quality when discussing cancer screening.

The web-based survey methodology does not allow us to directly compare responders to non-responders. However, the data set is weighted to adjust for demographic differences between those who responded and the characteristics of the population as a whole. Although weighting cannot correct for all nonresponse error, it does help to correct for variables that are correlated with key demographic characteristics.

Providing patients with decision aids to support informed decision making has been shown to increase knowledge and involvement in decision making, reduce decisional conflict, and, in the case of PCa, reduce screening.^{33,34} Interestingly, participants who underwent PCa testing were the least likely of those tested for cancer to be satisfied with their decision. This finding could reflect the

impact of widely publicized expert opinions that the harm of PCa screening outweighs the benefits.^{35,36} Conversely, it could also reflect an adverse event associated with a negative prostate biopsy.³⁷ Data were not collected on test results or biopsies. Surprisingly, however, men discussing PCa screening frequently reported that the healthcare provider was mainly responsible for the decision. Although patient preferences for the degree of decision involvement vary, most want to be offered choices and asked their opinions.³⁸ Finally, feeling highly informed about cancer screening was the factor most strongly associated with decision confidence among study participants, though it is uncertain whether they truly were more knowledgeable. The DECISIONS survey suggested that feeling informed correlated poorly with performance on knowledge testing.³⁹

Conclusions

Most participants in this national survey underwent cancer screening and were very confident in their decisions. Decision processes, however, did not routinely meet SDM criteria, often failing to address the potential harm of screening or elicit patient preferences. Healthcare providers likely need more training in SDM as well as tools such as decision aids to help facilitate these discussions. Greater decision confidence was associated with perceptions of higher cancer risk and feeling highly informed about the cancer screening decision. Supporting SDM by better educating patients about the risks and benefits of screening and normalizing cancer risk perception could potentially improve the quality of cancer screening discussions. However, highlighting the uncertainties surrounding cancer-screening decisions might not increase patient decision confidence.³⁹

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