

# Patient Preferences for Colorectal Cancer Screening

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**BACKGROUND.** New guidelines include several options for colorectal cancer screening. The goal of this study was to assess patient preferences for five approaches: no screening, fecal occult blood testing (FOBT), flexible sigmoidoscopy, barium enema, and colonoscopy.

**METHODS.** Patients from offices of primary care providers listened to a scripted oral presentation while viewing a table describing five screening methods and their outcomes. Immediately following the presentation, the subjects completed a questionnaire assessing their most preferred screening option and their likelihood of undergoing each option.

**RESULTS.** One hundred subjects aged 50 to 75 years participated. The average age was 64 years; 54 of the subjects were women, and 87 were white. Ninety-six percent of patients preferred to be screened by some method. When asked which test they would choose as their primary method of screening, 38% preferred colonoscopy, 31% preferred FOBT, 14% preferred barium enema, and 13% preferred flexible sigmoidoscopy. When asked how likely they would be to undergo each procedure on a 5-point scale, patients rated FOBT highest with an average score of 4.4, followed by colonoscopy (3.4), barium enema (3.4), flexible sigmoidoscopy (3.4), and no screening (1.5). Acceptance rates for these tests when recommended by their physician were 96% (FOBT), 82% (flexible sigmoidoscopy), 92% (barium enema), and 86% (colonoscopy).

**CONCLUSIONS.** Patients indicated a strong preference for colorectal cancer screening, but they did not indicate a dominant preference for any single screening test. Physicians need to take into account individual patient preferences when making recommendations regarding colorectal cancer screening.

**KEY WORDS.** Colorectal neoplasma; preventive health services; practice guidelines; patient acceptance of health care; patient preferences (Non MeSH). (*J Fam Pract* 1997; 45:211-218)

Colorectal cancer is the second most common cancer in the United States. Each year close to 150,000 cases of colon and rectal cancer are diagnosed and more than 55,000 Americans die as a result of colorectal cancers.<sup>1</sup> When adenomas are discovered at a pre-malignant stage, they can often be easily removed by colonoscopy, thereby preventing colorectal cancer. Studies have shown reduced rates of

colorectal cancer or mortality with colorectal cancer screening.<sup>2,5</sup>

National guidelines have been established by the American Cancer Society,<sup>6</sup> American College of Physicians,<sup>7</sup> and the United States Preventive Services Task Force.<sup>8</sup> These recommendations take into consideration efficacy, effectiveness, risks, and occasionally cost, but not patient preferences. Patient preferences are especially relevant to colorectal cancer screening because the available options differ considerably in relative effectiveness and in the nature and the probability of adverse effects.

The objective of this study was to identify which screening method patients would prefer if informed of the various options with a balance sheet. A *balance sheet* is a list of possible outcomes that assists a patient or provider to make an informed decision

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regarding alternative interventions.<sup>9,10</sup> An *outcome* is a benefit or harm to the patient, such as a potential complication, change in life expectancy, or the details of a procedure. The balance sheet presents this information, along with the probability that the outcome will occur for each option. By condensing the pertinent information onto a single, structured balance sheet, the patient or provider is able to more easily consider the possible outcomes before making a decision.

Balance sheets have been used previously in clinical decision-making and in the implementation of national guidelines. Still, despite the importance of patient preferences, these preferences are rarely used in the development of a guideline. For example, the recent Agency on Health Care Policy and Research guideline on benign prostatic hyperplasia includes a balance sheet and suggests its use in patient care.<sup>11</sup> Previous work by Eddy<sup>12</sup> included a balance sheet comparing some of the risks and benefits of colorectal cancer screening regimens for high-risk patients, but these data were not used to assess patient preferences. Eddy did discuss the presentation of a balance sheet to 100 randomly selected patients but has stated that "unfortunately, this question [of preference] has never been asked."<sup>13</sup> In the current study, individual patients were presented with a balance sheet designed to compare the potential risks and benefits of colorectal screening options for average-risk patients. The options assessed were those proposed by the American Gastroenterological Association.<sup>14</sup> The American Cancer Society recommendation is currently under review.

## METHODS

A balance sheet (Table 1) comparing the outcomes of five colorectal cancer screening methods was compiled using MEDLINE search references and data from the 1995 Office of Technology Assessment publication *Cost-Effectiveness of Colorectal Cancer Screening in Average-Risk Adults*.<sup>15</sup> The balance sheet was supplemented by pie charts designed to graphically represent the absolute probability and relative risk of developing colorectal cancer and dying of colorectal cancer with each of the screening options.

Patients aged 50 to 75 years from three primary care offices located in San Diego County, California, were eligible. Two of the sites were university-based

internal medicine faculty practices, one specializing in geriatrics. The third site was an internal medicine practice that is part of a community-based multispecialty group. Patients who had a previous diagnosis of colorectal cancer were excluded. Table 2 provides demographic information about the study population. Most patients were white and had at least a high school education, and most had undergone previous colorectal cancer screening. Written consent was obtained using a consent form approved by the Human Subjects Committee of the University of California, San Diego.

Three interviewers were enlisted for this project. A single interviewer sat in the primary care physician's office on selected half-days. Each eligible patient in the waiting room was approached, and each participating patient listened to a scripted oral presentation while the interviewer systematically presented the balance sheet and pie charts. The presentation was given in a private room and lasted approximately 10 minutes. All interviews occurred in August and September 1995.

Immediately following the presentation, the patient completed a preference assessment. Given the importance of how the question is framed in determining an individual's response, preference was assessed with three approaches by using the following question and statements:

- Considering the risks and benefits of colorectal cancer screening, if you were asked to select one of these options, which one would you choose?
- Considering the risks and benefits of colorectal cancer screening, please evaluate how likely you would be to undergo each of the following (with each option listed to be ranked on a 5-point Likert scale).
- I would want/I would not want to have this test if it were recommended by my physician. (Asked for each option.)

In addition, subjects were asked about their experience with the screening procedures, their risk factors for colorectal cancer, whether they had a family history of colorectal cancer, and demographic variables including age, sex, ethnicity, and level of education.

## STATISTICAL ANALYSIS

Eddy has proposed that for a particular method to be

TABLE 1

A Balance Sheet of Colon Cancer Screening Tests Used in Study of Patient Preferences

Event	Without Screening	Fecal Occult Blood Test	Flexible Sigmoidoscopy	Barium Enema	Colonoscopy
Description of test	No testing	You place 2 samples of stool onto special cards for 3 consecutive days and then mail them to your doctor for analysis	A flexible tube with a television camera at the tip is placed into your rectum and can examine approximately half of your colon	You are given an enema of a liquid which can be seen on x-ray films. Multiple x-ray films are taken with you lying in different positions	A flexible tube with a television camera at the tip is placed into your rectum and examines your entire colon. If polyps are found, they can be removed and biopsied
Preparation required for the test	None	For 5 days, you must alter your diet so as not to eat any red meat, certain fruits and vegetables, or vitamin C	You must give yourself two enemas 1 hour before the procedure	You must drink a laxative solution the evening before the test, which causes diarrhea to clear your colon	You must drink a laxative solution the evening before the test, which causes diarrhea to clear your colon. You cannot take aspirin or non-steroidal anti-inflammatory medicines for 1 week before the procedure
Intravenous sedation for test	No	No	No	No	Yes
Time required for test	None	A few minutes	15 minutes	30 minutes	45 minutes
Time missed from work for test	None	None	2-3 hours	2-3 hours	Entire day
How often test should be repeated	Not applicable	Every year	Every 3-5 years	Every 5 years	Every 5-10 years
Likely discomfort associated with the test	None	Process associated with obtaining stool samples from toilet	Mild sensation of urge to have bowel movement and possibly crampy abdominal pain	Mild abdominal pain	Mild sensation of urge to have bowel movement and possibly crampy abdominal pain
Risk of making hole in the colon which will require hospitalization, and may result in surgery or death.	0	0	0-4 / 10,000 <sup>12, 15, 16, 17</sup>	0-4 / 10,000 <sup>12, 15, 16, 18</sup>	10-20 / 10,000 <sup>12, 15, 16, 19</sup>
Probability of developing colon cancer over the rest of one's life <sup>2</sup>	53/1000	49/1000	38/1000	22/1000	18/1000
Probability of dying as a result of colon cancer over the rest of one's life <sup>2</sup>	25/1000	19/1000	14/1000	7/1000	6/1000
Colorectal cancers prevented, %	None	10-38 <sup>20-22</sup>	45 <sup>3</sup>	40-70 <sup>15</sup>	58-87 <sup>23</sup>
Decrease in colorectal mortality as a result of screening procedure, %	0	20-33 <sup>2, 24</sup>	45-70 <sup>3, 4, 25</sup>	45-70 <sup>15</sup>	70-80 <sup>4, 5</sup>
Chance that the screening test will be positive and result in the need for a colonoscopy over 10 years, %	0	40 <sup>2</sup>	8-13 <sup>17, 26-29</sup>	30-40 <sup>16</sup>	Not applicable
Unit cost per procedure, \$	None	5-10 per procedure <sup>12, 15</sup>	80-135 per procedure <sup>12, 15</sup>	131-200 per procedure <sup>12, 15</sup>	285-500 per procedure <sup>12, 15</sup>

dominant over others there should be a "virtual unanimity" (ie, at least 95% ) of patients agreeing on the desirability of the outcomes. He describes those guidelines that have this level of agreement to be "standards." "Guidelines," in Eddy's parlance, should have outcomes preferred by an appreciable majority (ie, 60% to 95% ) of patients.<sup>13</sup> The preferences of the subjects in this study, with their 95% confidence intervals, were compared.

Given that there was no dominant preference, we evaluated potential differences in preferences in a secondary analysis. Patients seemed to prefer the fecal occult blood test (FOBT) or colonoscopy over flexible sigmoidoscopy or barium enema, although the order of the preference depended on the preference assessment method. Because of this apparent domination of FOBT and colonoscopy, initial hypotheses tested for differences between these two procedures. The likelihood ratio test with a chi-square approximation was used to test the hypothesis that the probability of choosing FOBT and the probability of choosing colonoscopy were equal when subjects were asked to list their most preferred screening option. For the Likert-scale question, the hypothesis that the probabilities of choosing the Likert-scale categories was the same for FOBT and colonoscopy was tested using the chi-square test of homogeneity. For all other questions, the hypothesis that probabilities were equal was tested using the normal approximation to the binomial distribution and a two-tailed significance test.

**RESULTS**

A total of 100 patients participated in the study. The mean age was 64 years (50 to 75 years), and 54% were women (Table 2). All patients who agreed to participate listened to the entire presentation and completed a questionnaire. Less than 10% of the patients who were asked to participate declined, with lack of time given as the primary reason. The one patient whose condition had previously been diagnosed as colon cancer was excluded from the study. A language barrier was not a problem for any of the participants.

Ninety-six percent of patients preferred to be screened for colorectal cancer by one of the four options, thus making colorectal cancer screening a "standard" according to Eddy's criteria. When asked which test they would choose as their primary

**TABLE 2**

**Characteristics of Patients in the Study (N = 100)**

Variable	%
<b>Age, y</b>	
50-55	16
56-60	17
61-65	19
66-70	23
71-75	25
<b>Sex</b>	
Male	46
Female	54
<b>Race/Ethnicity</b>	
White	87
Hispanic	7
Asian	4
Black	2
<b>Education</b>	
<High school graduate	2
High school graduate	59
College graduate	25
Graduate degree	14
<b>Prior colorectal cancer screening</b>	93

method of screening, 38% (95% CI = 0.28 to 0.48) preferred colonoscopy and 31% (95% CI = 0.22 to 0.40) preferred FOBT, followed by barium enema and flexible sigmoidoscopy (Table 3). This indicates that there is no single approach to colorectal cancer screening that dominates patient preference.

There was no difference in the preference for colonoscopy and FOBT ( $\chi^2 = 7.11, df = 1, P = .40$ ). Colonoscopy was preferred over barium enema ( $\chi^2 = 11.51, df = 1, P = .0007$ ), and FOBT was preferred over barium enema ( $\chi^2 = 6.58, df = 1, P = .01$ ). When asked how likely they would be to undergo each procedure, patients rated FOBT highest with a mean score of 4.4, followed by colonoscopy, barium enema, flexible sigmoidoscopy, and no screening (Table 3); (FOBT preferred over colonoscopy:  $\chi^2 = 31.40, df = 4, P < .0001$ ). If recommended by their physician, 96% of patients said that they would be willing to complete the FOBT screening. Similarly, willingness to comply with a physician's recommendations was reported for colonoscopy, barium enema, and flexible sigmoidoscopy (Table 3); (FOBT

preferred over colonoscopy:  $z = 2.51, P = .01$ ). More patients had undergone FOBT (78%) than colonoscopy (28% ;  $z = 8.18, P < .0001$ ). Of the patients who had previously undergone colonoscopy, 71% (20/28) preferred to have a colonoscopy as their method of screening. Patients who had previously undergone other tests were less likely to prefer those tests (Table 4); (colonoscopy preferred more often than FOBT,  $z = 5.30, P < .0001$ ).

**DISCUSSION**

Over the past several decades the ethics of medicine has moved from a physician-dominated, paternalistic approach to a philosophy dominated by patient-centered autonomy.<sup>30</sup> While the ethics of clinical care has changed, most guideline panels do not consider patient preferences. Instead, the panel analyzes the available data and recommends what it considers the most appropriate course. When the choice among various options is clear, this may be an appropriate expediency. Many guidelines, however, involve clinical decisions that are less obvious. In these cases the assessment of patient preferences should be an essential element in the guideline development process.<sup>10</sup> There is no single best choice for colorectal cancer screening. The options vary from a simple, yearly, inexpensive test that is relatively inaccurate (FOBT) to colonoscopy, a higher risk, invasive, and relatively accurate procedure that may

need to be performed only every 5 to 10 years. This study represents the first attempt to assess patient preferences about available colorectal cancer screening approaches.

When given a choice, patients clearly preferred to undergo some form of colorectal cancer screening. Patients did not have a distinct preference for any one screening method, but they tended to prefer colonoscopy or FOBT screening over barium enema or flexible sigmoidoscopy. Their attitudes toward the colorectal cancer screening options varied, however, when their views were elicited by the three different preference questions. When asked to select one test that they most preferred, both colonoscopy and FOBT were preferred over other methods, without a significant difference between the top options. When asked to rank how likely they would be to undergo each of the screening options, FOBT received the highest mean rating. When questioned about their willingness to undergo each of the screening tests if it were recommended by their physician, the vast majority of patients indicated that they would be willing to undergo any of the four options, although FOBT was preferred more frequently than colonoscopy. Finally, of those patients who had previously undergone one or more tests, more preferred colonoscopy than any other option. Perhaps more significantly, colonoscopy was the only procedure for which prior experience appeared to alter the preference rate.

**TABLE 3**

**Patient Preferences of Test Options as Assessed by Three Different Approaches (N=100)**

	No Screening	Fecal Occult Blood Test (FOBT)	Flexible Sigmoidoscopy	Barium Enema	Colonoscopy
% of patients who selected test as 1st preference*	4	31 (0.22 - 0.44)†	13	14	38 (0.28 - 0.48)†
Mean likelihood of patients' undergoing test (1 = highly unlikely, 5 = highly likely)‡	1.6	4.4	3.4	3.4	3.4
% of patients who would undergo test if recommended§	N/A	96	82	92	86

\* Colonoscopy vs FOBT,  $P = .40$ ; colonoscopy vs barium enema,  $P = .0007$ ; FOBT vs barium enema,  $P = .01$ .

† 95% confidence interval.

‡ FOBT vs colonoscopy,  $P < .0001$ .

§ FOBT vs colonoscopy,  $P = .01$ .

TABLE 4

Patient Preferences According to Prior Experience with Colorectal Cancer Screening Tests

Variable	No Screening	Fecal Occult Blood Test (FOBT)	Flexible Sigmoidoscopy	Barium Enema	Colonoscopy
% of patients who have had this colorectal cancer screening test*	7	78	46	48	28
% of patients who have had this test and who prefer this screening test†	14	36	17	15	71

\* FOBT vs colonoscopy, *P*<.0001.

†Colonoscopy vs FOBT, *P*<.0001.

This diversity of subject responses highlights the critical importance of how the phrasing of the question often influences the response. Certainly, the field of patient decision-making is an important area for research.<sup>31</sup> This research should address not only how the different questions affect the responses, but which questions are the most relevant for clinical and policy purposes. Until more is known, care should be taken when considering the results of any patient preference study.

Given the recent work of the American Gastroenterological Association,<sup>14</sup> any of the four approaches to colorectal cancer screening are reasonable options, with the final decision perhaps a matter of patient preference. Many clinicians may be disappointed in the findings of the current study. Indeed, had we found a strong, solitary preference among patients, then the clinician's job would be much easier. We could find no dominant preference, however. While colonoscopy and FOBT seemed relatively dominant, even flexible sigmoidoscopy and barium enema were preferred by a substantial proportion of the patients. Thus, our findings suggest that when confronted with an individual patient in the examination room, the clinician should offer information on all four colorectal cancer screening methods.

One interesting finding was the strong preference (71%) for repeat colonoscopy in those who had a previous colonoscopy and the relatively weak preference (36%) for repeat FOBT in those who had previously experienced FOBT. The exact rationale for this observation requires additional

study, but one possible explanation relates to the completeness of the evaluation. A patient who had a negative FOBT in the past may feel that a repeat evaluation would not be worth it. After all, it might be argued, if cancer is present, the FOBT already missed it once, so a more sensitive test might be justified. A similar rationale could apply to those who had a past colonoscopy: why "settle" for a less sensitive test after already having undergone the "gold standard." More work is needed in this area.

Ultimately, the patient will choose whether or not to participate in a colorectal cancer screening program. Given the evidence that colorectal cancer screening can save lives and is cost-effective, the key question is how to best present patients with colorectal cancer screening options. Our work suggests that any screening program that emphasizes only one or two options (eg, just FOBT and flexible sigmoidoscopy) will not appeal to as many patients as one that offers all four options. In contrast, programs with multiple options may be more difficult to implement in a busy clinician's practice. This presents a difficult dilemma. A screening program that offers only one or two options may have lower compliance because of patient factors; that is, not all patients are offered a program they prefer. On the other hand, a more comprehensive program that offers more options may have lower compliance because of clinician factors (unable to implement in a busy practice) and patient factors (overwhelmed by the variety of choices). Clearly, more work is needed prior to final policy recommendations.

There are several limitations to this study. First, the subjects who participated in it were scheduled to see their provider for an acute or chronic medical problem, as opposed to a health maintenance visit. Nevertheless, the patients represent those whom primary care physicians see in their offices and to whom they make recommendations regarding colorectal cancer screening.

Second, the patients represent a convenience sample from several southern California primary care practices. The patients' demographic characteristics (eg, predominantly white and educated) may have influenced our findings. It is important to note, however, that the major finding of our study is the *lack* of agreement among the study population. If this relatively homogeneous population has different preferences, it is unlikely that a more representative sampling of the general population would show less diversity. It should be noted that the overall high rate of acceptance of colorectal cancer screening may have been influenced by the demographics of the population. Further work is needed in communities with different ethnic backgrounds.

Third, the population had a relatively high rate of previous experience with these screening tests (Table 4), with about one fourth of the patients having had a prior colonoscopy. Again, the major finding of the study is the diversity of patient preferences. The study population had an unusually good record for previous screenings. While this may limit the generalizability of their preference assessments, it is not clear that a population with less experience with these procedures would have a stronger preference for a single screening method.

Fourth, while the balance sheet describes the cost of the procedures, the patients were left to decide who would pay for the procedure. In the end, cost was not a significant factor in the patients' preferences as assessed in a series of logistic regressions on the preference for each screening method considering each of the three preference questions (data not presented).

Finally, patients often have difficulty understanding several key concepts (eg, probability, absolute risk, and relative risk). While this limitation is serious, we spent more time with each subject than is common in clinical practice, and the use of pie charts as a visual aid likely assisted the subjects' understanding of these important con-

cepts. This remains an important area for future study.

## CONCLUSIONS

While the debate regarding national recommendations for colorectal cancer screening continues, physicians must make their own decisions regarding these issues on a daily basis. These decisions are being made with little input from the people they most affect—the patients. This study shows that patients have preferences, and these preferences are very diverse. Both clinicians and policy makers should consider the preferences of patients when making recommendations regarding colorectal cancer screening.

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